



**HCFA ON-LINE: MARKET RESEARCH  
FOR BENEFICIARIES  
THIRD FOCUS GROUP REPORT**

**D R A F T**

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# **Market Research on the Information Needs of HCFA Beneficiaries Medicare Subpopulation Focus Groups**

## **1. INTRODUCTION**

The Health Care Financing Administration (HCFA) market research initiative was developed to improve HCFA's service to its customers and partners and to promote effective communication strategies while incorporating innovative technologies and systems. The four components of the overall market research initiative include: (1) identifying the information needs of HCFA customers through market research; (2) improving the usefulness of HCFA data and information; (3) enhancing communication capabilities; and (4) developing formal evaluation and feedback mechanisms to ensure continuous improvement of HCFA activities. The focus group research reported here is part of the HCFA market research effort to identify the information needs of Medicare beneficiaries.

### **1.1 OVERVIEW OF THE MARKET RESEARCH PROJECT ON THE INFORMATION NEEDS OF HCFA BENEFICIARIES**

The Market Research for Beneficiaries initiative is dedicated to helping HCFA understand the flow of information between HCFA and Medicare beneficiaries. The market research activities focus on two questions:

- What information do beneficiaries want and need from HCFA?
- How can that information be most effectively made available?

Our goal is to implement data collection and analysis activities that will help HCFA understand beneficiaries' information needs and identify effective communication strategies. We are conducting three data collection activities: an inventory of information needs and effective communication and dissemination strategies, focus groups with Medicare beneficiaries, and surveys of the Medicare population. While complementary, each of the three data gathering approaches has particular strengths that will contribute to a more thorough overall understanding of the research questions. For example, the inventory research ensures that information about strategies for identifying and addressing beneficiaries' needs and preferences builds on the cumulative experience of diverse organizations involved in distributing information about health care, health care services and health care options. The focus group research is collecting detailed qualitative information from current Medicare beneficiaries and from individuals about to enroll in the Medicare program. The Medicare beneficiary

survey activities provide a mechanism for producing population estimates reflecting individuals' attitudes toward and needs for information.

In order for HCFA to respond to the varying needs of a diverse Medicare population, the Market Research for Beneficiaries project is being conducted in three phases that are illustrated in Exhibit 1-1. The focus of the first phase was the general Medicare population. It included an inventory of communication strategies effective with Medicare beneficiaries in general (see the First Inventory Report) and focus groups with individuals drawn from the general population of Medicare beneficiaries (see the First Focus Group Report). The Phase 1 research activities included analyses of results from survey research conducted with the general Medicare population. As illustrated in Exhibit 1-1, subsequent phases of the project provide similar types of information for selected groups of Medicare beneficiaries. Phase 2 research activities covered five beneficiary subpopulations: African-American beneficiaries, Hispanic beneficiaries, beneficiaries who are dually eligible for Medicare and Medicaid, rural beneficiaries, and those about to enroll in Medicare. Phase 3 research activities cover three beneficiary subpopulations: beneficiaries with low educational attainment, beneficiaries with hearing loss, and beneficiaries with vision loss. Within each research phase, the Market Research for Beneficiaries initiative produced separate inventory, focus group and survey reports for the selected Medicare subpopulations. The project's Synthesis Reports will integrate results across the three sets of research activities for each study subpopulation, focusing on implications for HCFA communication strategies.

### **Exhibit 1-1**

#### **Research Activities and Study Populations for Three Phases of Market Research**

<b>Research Phase</b>	<b>Research Activities</b>	<b>Study Populations</b>
Phase 1	Inventory Focus Groups Survey Data Collection Analysis	General Medicare Beneficiaries
Phase 2	Inventory Focus Groups Survey Data Collection and Analysis	African-American Beneficiaries Hispanic Beneficiaries Dually-Eligible Beneficiaries Rural Beneficiaries Individuals About to Enroll in Medicare
Phase 3	Inventory Focus Groups Survey Data Collection and Analysis	Beneficiaries with Low Educational Attainment Beneficiaries with Hearing Loss Beneficiaries with Vision Loss

The current report focuses on three beneficiary groups: beneficiaries with low educational attainment, beneficiaries with hearing loss, and beneficiaries with vision loss. The focus group research reported here builds upon our initial inventory and focus group research with beneficiaries from the general Medicare population. The goal of our Phase 3 focus group research was to collect information directly from beneficiaries within each of the selected Phase 3 beneficiary populations to:

- Explore beneficiaries' perceptions of the information available to them;
- Identify information gaps that beneficiaries are aware of;
- Investigate additional information gaps that beneficiaries become aware of through discussions of their experiences;
- Identify sources of information that are particularly accessible to beneficiaries;
- Identify sources of information that are trusted by beneficiaries; and
- Investigate beneficiary reactions to media and methods for communicating information about health and health care.

It is important to note that our aim with the Phase 3 focus groups is to understand information experiences, needs and preferences within each of the selected beneficiary subpopulations. Consequently, our data collection and analytic efforts focus on identifying important results within each of the selected subpopulations. This report is structured to present results separately for each group of beneficiaries. The next section of this report gives a more detailed overview of the organizational structure for this focus group report.

## **1.2 OVERVIEW OF FOCUS GROUP REPORT**

Chapter 1 of this focus group report gives an overview of the HCFA Market Research project on the information needs of HCFA beneficiaries. Chapter 2 gives general information about focus group methods and specific information about the Phase 3 focus group design. It includes descriptions of the focus group discussion guides, the focus group participants and our focus group analyses. Chapters 3 through 5 present our major findings. Chapter 3 presents results relating to beneficiaries' information needs. Chapter 4 presents results relating to beneficiaries' attitudes toward alternative sources of information. Chapter 5 presents results relating to beneficiaries' reactions to and impressions of alternative information channels or media. We use quotations from focus group participants extensively in Chapters 3 through 5 to illustrate our main findings. The quotations are presented in text boxes to make them easy to identify. In addition, we use text box titles to highlight findings that the quotations were selected to illustrate.

Chapters 3 through 5 begin with summaries of major results from focus groups conducted with individuals drawn from the general population of Medicare beneficiaries. Then, the chapters present focus group results separately for each of the three selected groups of HCFA beneficiaries. This structure reflects our major goal: to identify information experiences, needs and preferences, separately for each of the selected groups of beneficiaries. In Chapters 3 through 5, we use italic font to emphasize preliminary implications suggested by focus group results.

The results presented here are only one resource for the HCFA Market Research for Beneficiaries initiative. As illustrated in Exhibit 1-1, we have conducted focus groups with other beneficiary populations. Also, our market research design includes literature review activities, intensive interviews with experts who have considerable experience developing and delivering information for Medicare beneficiaries, and surveys of the Medicare population. Given the complementary strengths of these data collection methods, it is important to note that implications identified here will be amplified, modified or revised based on results from the other market research components and phases. Chapter 6 synthesizes major results about information needs, preferred information sources, preferred information media and preliminary recommendations for each Phase 3 study subpopulation. An important goal of the project's Synthesis Reports will be to identify a fully informed set of recommendations developed by considering results from different research activities, separately for each study population.



## 2. FOCUS GROUP METHODS AND DESIGN

### 2.1 OVERVIEW OF FOCUS GROUP METHODS

Focus group methods used in market research fall within the domain of qualitative research methods. The aim of focus group research is to explore participants' experiences, attitudes and motivations. Focus group research is descriptive and inductive. The goals of focus group research differ from and are complementary with the goals of program evaluation research and survey research which are designed to estimate and evaluate quantifiable phenomena (e.g., Taylor and Brogden, 1984; Patton, 1990). The aim of focus group research is to **understand** attitudes and experiences while the aims of survey and program evaluation research are to **quantify and estimate** attitudes and experiences.

With the qualitative focus on understanding individuals' experiences and perspectives, focus group methods typically involve small numbers of participants selected according to study-specific criteria. In addition, research protocols and discussion guides are open-ended to ensure that participants report their experiences using their own words. These characteristics highlight the strengths and limitations of focus group research. Focus group methods are particularly appropriate for collecting data on individuals' experiences with Medicare in terms that reflect their own perspectives and for generating hypotheses about the experiences of individuals in different situations or from different backgrounds. Focus group methods are generally not suitable for research that requires evaluating the prevalence of particular experiences within or across populations or drawing inferential conclusions about group differences.

### 2.2 FOCUS GROUP LOCATIONS

The focus groups reported here were conducted in seven locations: Chicago, Houston, Baltimore, San Antonio, Pittsburgh, Tampa, and Sarasota. These locations were selected to reflect a range of health care markets, based on documentation in the First Inventory Report that consumers' experiences and information needs are likely to differ depending on market factors. Exhibit 2-1 identifies the focus groups conducted in each location. For groups of beneficiaries with hearing or vision loss, we identified focus group moderators with particular expertise in those areas.

**Exhibit 2-1**  
**Focus Groups Conducted in Each Location**

<b>Location</b>	<b>Beneficiary Subgroups</b>
Chicago, Illinois	Low educational attainment (1 focus group)
Houston, Texas	Low educational attainment (1 focus group)
Baltimore, Maryland	Low educational attainment (1 focus group) Hearing loss (2 focus groups)
San Antonio, Texas	Low educational attainment (1 focus group)
Tampa, Florida	Vision loss (2 focus groups)
Pittsburgh, Pennsylvania	Vision loss (2 focus groups)
Sarasota, Florida	Hearing loss (2 focus groups)

### **2.3 FOCUS GROUP DISCUSSION GUIDE**

When effectively moderated, focus group interactions simulate conversations that might naturally occur around a given topic. The give-and-take among group members elicits ideas and reactions that might not be revealed in individual interviews. The focus group discussion guide is an important tool in helping moderators lead groups effectively. A good discussion guide helps moderators to encourage spontaneous participation, to react to group dynamics, to ensure participation from all group members, and to guide group discussion away from topics that are irrelevant to research goals while leaving room for the discussion to address unanticipated topics that are relevant to overall research goals.

We worked closely with HCFA project staff to develop initial discussion guides and to revise the discussion guide iteratively based on issues that emerged from ongoing inventory research and from early focus group discussions. We developed one discussion protocol that was sufficiently general to serve as the moderator's guide for most focus groups with current beneficiaries. We used the general beneficiary discussion guide to develop discussion guides tailored for focus groups with beneficiaries with hearing or vision loss. The three discussion guides covered the same set of general topics, but the specific discussion questions differed somewhat for focus groups with beneficiaries from the three study subpopulations. For example, all groups were asked about their reactions to alternative communication media. Focus groups with beneficiaries who had hearing or vision loss discussed a larger set of media that included media intended to address special sensory needs.

The focus group agenda and discussion guide topics were designed so that the groups would spend roughly half of each two-hour discussion talking about the **kinds** of information beneficiaries want

and need from HCFA and the other half of the discussion talking about **effective methods** for making information available to beneficiaries. It is clear from the focus group results in Chapters 3 through 5 that the guides were sufficiently open-ended to elicit subgroup specific information needs and concerns. Exhibit 2-2 gives an overview of the topics included in the discussion guides, and the moderator guides are included as Appendix A.

Two sections of the discussion guides were modified roughly half-way through the focus group data collection based on early results and emerging issues. In the sections focusing on information about supplemental insurance, we added questions about information on Medicare HMOs. The new discussion questions asked about the kinds of information participants received from Medicare HMOs and the kinds of information they would like to receive from Medicare HMOs.

**Exhibit 2-2**  
**Overview of Focus Group Discussion Topics**

<b>Focus Group Topics</b>
<p>Basic knowledge of Medicare program</p> <p>Familiarity with HCFA</p> <p>Recent Medicare information needs</p> <p>Recent attempts to get Medicare information</p> <p>Most important sources of Medicare information</p> <p>Most trusted sources of Medicare information</p> <p>Familiarity with and reactions to Medicare Handbook</p> <p>Gaps in Medicare information</p> <p>Information needs and preferred form:</p> <ul style="list-style-type: none"> <li>• Supplemental insurance</li> <li>• Medicare HMOs</li> <li>• Primary care providers</li> <li>• Specialty care providers</li> <li>• Staying healthy and preventative care</li> </ul> <p>Reactions to information media, including radio and television, newspapers and magazines, mail-out materials, videotapes</p> <p>Reactions to telephone resources, including automated response units (ARUs)</p> <p>Reactions to computerized resources, including the Internet</p>

## **2.4 FOCUS GROUP PARTICIPANTS**

HCFA provided lists of Medicare beneficiaries in the selected locations, and focus group participants were recruited by market research firms in most areas. The market research firms used the Medicare lists, their own lists of research participants, and other means of recruitment such as distributing flyers in senior centers and churches to identify eligible and interested participants. Early inventory results revealed that Medicare experiences and beneficiary information needs vary considerably depending on whether beneficiaries are enrolled in fee-for-service or managed care health plans. HCFA project staff decided early on that it would be counter-productive to recruit groups that mixed beneficiaries from fee-for-service and Medicare managed care plans. We conducted four focus groups for most of the selected subgroups of HCFA beneficiaries.<sup>1</sup> HCFA was concerned that the exploratory power of the focus group design would be diluted if half of the groups examined the experiences of beneficiaries under fee-for-service plans and half of the groups examined very different experiences of beneficiaries under Medicare managed care. HCFA has already completed several studies using qualitative research methods to explore beneficiaries' experiences with Medicare managed care (HCFA, 1995). Based on these considerations, HCFA determined that the groups included here should consist only of beneficiaries enrolled in fee-for-service plans.

For this phase of the Market Research for Beneficiaries project, the subpopulations of interest are those with low educational attainment, those with hearing loss, and Medicare beneficiaries with vision loss. We defined "low education" as formal education of high school or less. The criterion for participation in the low hearing and vision loss groups was having "a lot of difficulty" hearing or seeing (with glasses/a hearing aid). Our focus group screening questionnaires are included in Appendix B. Recruiters were instructed to fill focus groups with men and women, and a mix of ages. The groups were also recruited to reflect a mix of races or ethnic backgrounds. To identify Medicare beneficiaries with hearing or vision loss, we developed specialized recruiting procedures. For these study subgroups, we worked through consumer groups and professional organizations to identify and recruit participants. Exhibit 2-3 gives detailed demographic information about focus group participants for each study subpopulation.

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<sup>1</sup> We conducted eight focus groups with Hispanic beneficiaries.

## **2.5 SPECIAL ARRANGEMENTS**

We made some special arrangements to ensure full participation from participants with hearing or vision loss. We used microphones connected to an audio-loop to facilitate discussion in groups of beneficiaries with hearing loss. One participant with hearing loss required additional computerized transcription.

We eliminated the card sorting task for participants with vision loss. In these groups, moderators led discussions on frequent sources and on trusted sources of information. The moderator guide for focus groups with vision loss in Appendix A shows the discussion questions we used in those focus groups to replace the card-sorting tasks.

## **2.6 FOCUS GROUP DATA ANALYSIS**

The basic questions this research seeks to answer are:

- What information do Medicare beneficiaries want and need?
- How would they like to get it?

The focus group discussion guides were structured to collect extensive information on both general topics, and the discussion data permit in-depth review and analysis. All focus group discussions were recorded on videotape and on audiotape. Discussion transcripts were made from the audiotaped discussions. These transcripts were our primary analytic resource. In addition, note-takers were present at all groups to take detailed notes on discussion content and flow. Note-takers documented important features of the composition and dynamics in each group and drafted summaries for most groups. The summaries identified important group characteristics and preliminary findings. The summaries and the video- and audiotapes were secondary analytic resources. We used these materials to clarify and sharpen our analytic conclusions.

We conducted all focus group analyses separately by selected beneficiary subpopulation. This report focuses on three subpopulations: beneficiaries with low educational attainment; beneficiaries with hearing loss; and beneficiaries with vision loss. Based on initial reviews of group transcripts and summaries, we identified major themes and topics for each subpopulation. We sorted electronic versions of the transcripts by topic so that we could review what beneficiaries from the selected subpopulations had to say about each general theme or topic. All quotations in the sorted transcript files were identified by group location and population, so it was possible to compare experiences and perceptions across locations. Some qualitative comparisons across subpopulations are also possible, but this report will

focus on themes that emerged from the analyses performed separately for each selected subpopulation. The themes address the two general research questions, around which this report is organized.

Chapters 3 through 5 present the results from our focus group analyses. Chapter 3 focuses on identified beneficiary information needs, Chapter 4 addresses beneficiary perceptions of alternative information sources, and Chapter 5 details beneficiary reactions to and preferences across alternative information media. In these chapters, we have presented results separately for each subgroup to make it easy for readers interested in particular subpopulations to find relevant results. We start each chapter with a brief summary of major findings from the first focus group report. These summaries give overviews of results from focus groups with individuals drawn from the general population of Medicare beneficiaries. These summaries provide a baseline for evaluating results from other subpopulations. Chapter 6 synthesizes results from Chapters 3 through 5 for each study subpopulation. The later Synthesis Reports will make comparisons across the research methods for each subpopulation selected for study in this market research initiative.

**Exhibit 2-3**

**Demographic Characteristics of Focus Group Participants by Beneficiary Subgroup**

	<b>U.S. Pop. Over 65</b>	<b>General Pop.</b>	<b>Low Vision</b>	<b>Hearing Loss</b>	<b>Low Education</b>
<b>Number of Groups</b>		12	4	4	4
<b>Gender</b>					
Male	40.8	51.0	40.6	48.6	40.6
Female	59.2	49.0	59.4	51.4	59.4
<b>Age Group</b>					
65-69	29.6	50.0	12.5	11.4	46.9
70-74	26.3	25.5	6.3	22.9	37.5
75 and older	44.1	23.6	81.3	65.7	15.6
<b>Race/Ethnicity</b>					
White, not Hispanic	86.2	84.7	96.9	97.1	53.1
Black	7.2	13.3	0	2.9	31.3
Hispanic	4.5	1.0	3.1	0	9.4
Other	2.0	1.0	0	0	6.3
<b>Education</b>					
Less than high school	31.1	7.6	21.9	5.7	64.5
High school graduate	36.4	31.4	31.3	8.6	25.8
Some college	18.3	32.4	18.8	14.3	9.7
College graduate	9.0	20.0	15.6	34.3	0
Advanced degree	5.2	9.5	12.5	37.1	0
<b>Level of vision loss</b>					
No loss	62.0	N/A	0	N/A	N/A
Some loss	37.5	N/A	19.4	N/A	N/A
Severe loss	0.5	N/A	80.6	N/A	N/A
<b>Level of hearing loss</b>					
No loss	57.6	N/A	N/A	0	N/A
Some loss	42.2	N/A	N/A	48.6	N/A
Severe loss	0.2	N/A	N/A	51.4	N/A
<b>Previous Focus Group Experience</b>					
Yes	N/A	61.9	9.4	26.5	33.3
No	N/A	38.1	90.6	73.5	66.7

### 3. INFORMATION NEEDS OF MEDICARE BENEFICIARIES

The focus group protocol dealt with the information needs of beneficiaries in several areas: information about the Medicare program, information about supplemental insurance, information about choosing a health care provider, and information about staying healthy. In early groups, we attempted to exclude information about Medicare HMOs from the protocol because considerable qualitative research has been done on beneficiaries' needs for information about choosing an HMO and using managed care effectively (e.g., HCFA, 1995). Nevertheless, focus group participants often wanted to talk about managed care, and their comments revealed experiences and information needs that seemed important to this market research initiative. Therefore, we revised the focus group protocol roughly half-way through the research project to include specific questions about the types of information participants have received from Medicare HMOs and the types of information they would like to receive about Medicare HMOs. The revised guide was used with focus groups conducted in Baltimore and San Antonio.<sup>2</sup> This chapter includes a section on "information about managed care" which covers results from early groups that were conducted before the guide was revised, as well as results from later groups where Medicare HMOs was explicitly included as a discussion topic.

#### 3.1 MAJOR FINDINGS FOR GENERAL POPULATION BENEFICIARIES

Broadly speaking, focus group participants from the general population of Medicare beneficiaries need two kinds of information: **general** information about the Medicare program and its structure and **situation-specific** information about how beneficiaries with specific needs can use the program to access care. The information that beneficiaries need most depends on health status, the presence of precipitating health events, and beneficiary information-seeking strategies: whether they are proactive, reactive or passive information-seekers. Proactive information-seekers look for information from a variety of sources on a continual basis. They value accurate, up-to-date information, and generally make their own judgments about what's useful and what isn't. Reactive information-seekers look for answers to questions or problems as they arise, they prefer to access only information that is relevant to their immediate situation, and they usually don't want to have to pursue more than one source. Passive information-seekers seem to lack specific strategies for gathering information they need. They rely on information that is delivered to them automatically and on information from trusted advocates or resources.

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<sup>2</sup>The revised moderator's guide was used in other locations, and those results were reported in earlier focus group reports.



## BASIC PROGRAM INFORMATION

Most participants in the general population focus groups were familiar with the Medicare program's basic features. They were confused about more detailed aspects of the program. Conversations revealed a reasonably high comfort level with the relationship between primary and secondary payers, and the distinctions between Medicare Parts A and B. However, in addition to often incorrectly identifying Medicare as a program run by the Social Security Administration, participants frequently had trouble differentiating among the Medicare program, the agency that administers Medicare, carrier insurers that pay claims for Medicare, and supplemental insurers.

### **Confusion about who administers Medicare**

Participant: I get from Social Security [information] about the Medicare... If there's anything they want us to know, my experience is it comes through them.

Moderator: Okay, that's Social Security, but we're talking about Medicare, the health insurance part.

Participant: But it amounts to the same thing, is what I was going to say.

Respondents reported that recent experiences trying to find information about the Medicare program were generally motivated by problems obtaining and/or paying for care. Participants gave mixed accounts of the outcomes of these experiences. Some were satisfied with the answers provided by such sources as the Explanation of Medicare Benefits form (EOMB), the Medicare Handbook, or their doctors. Others were unable to describe their coverage and did not recognize that there were existing resources to answer their questions about Medicare conventions and procedures. A large number of participants were uncertain about where to find information on benefits and coverage, and some of these beneficiaries were able to resolve their problems only through serendipitous contacts with resources who were willing to advocate for them.

### **Beneficiaries rely on a variety of resources**

The rules state that... they are supposed to pay it so long as that letter is accompanied with that claim... they claimed in our case that they never received a letter... I volunteer at the hospital so I know some of the people there. And I went down to one of the girls who handles it and I explained the situation. She said, 'Leave it with me and I will take care of it.' Now how she did it I don't know but she did get it taken care of in her own way.

I had bypass surgery and I handled all my paperwork... Well, I think that at last count my bills were two inches thick... But if it weren't for the Medicare Explanation of Benefits, which I think are wonderful, I could not nail down the providers when they make errors... I Xeroxed Medicare Explanation of Benefits and say, 'Haven't you looked at this?'... I want to applaud them.

Participants reported difficulty interpreting the terminology they encounter on Medicare billing and information materials. Although some participants were aware that HCFA provides definitions of terms on such forms as the EOMB, others suggested adding a glossary to the Medicare Handbook. Participants reported that they often learn to navigate the Medicare system by trial-and-error, which means that they often experience frustration in sifting through contradictory information. In some cases, participants reported receiving correct information about coverage only after services were provided.

#### **Learning about Medicare through experience and trial-and-error**

The information sheets that are prepared by computer are absolutely obscure... They use terminology that there's no dictionary for. There's no glossary provided. And the syntax they use is archaic.

Well, I'm fairly new. I just started in February. I have found that I don't really know what's going on... Some of the doctors don't charge me anything... Some of the doctors make me pay... It's very confusing to me.

What I finally figured out is, most of the doctors send it to Medicare. Medicare sends it to [my supplementary insurance] and then whatever didn't get paid, the doctor bills for.

My wife needed therapy and... I listened to the doctor which is probably mistake number one. He says, 'Don't worry, you are covered by Medicare'... We went to the hospital for the therapy that she needed and when it came time to pay, the hospital sent me a bill that was larger than what Medicare paid... They said that Medicare pays 20 percent of what the hospital bills... In other words, the hospital billed \$1,000, Medicare approved \$500, they paid 80 percent of the \$500. I was billed 20 percent of the full \$1,000.

But the problem, again, is lack of information in terms of accessibility to the patient. The provider and the payer may know what they're talking about, but the patient, in most cases, hasn't the foggiest notion of what the arrangements are... I think we have to have full disclosure. We need to know what's going on.

## **CHOOSING A PROVIDER**

A few participants from the general population reported that they use medical associations and reference books to choose their medical providers. The rest were more likely to rely on recommendations from other trusted providers, friends and family, or on their own personal experiences. Participants generally agreed that training, certification status, and record of malpractice suits are important factors to consider when looking for qualified providers. Participants were also interested in assessing the communication skills or "bedside manner" of a potential primary care provider. Participants reported relying on advice from friends and family and their own experiences to gather information about interpersonal skills. Participants were not interested in accessing this kind of information through

published provider lists or referral services. Participants generally agreed that they rely on their primary care providers for referrals to specialists.

Selecting a provider: Criteria and resources
<p>If someone gave me a list of doctors... some information on a list of doctors, I still wouldn't know which one to pick until I got right down to the nitty gritty and talked to him.</p> <p>You go to your friends who have been dealing with a doctor for quite a few years. Find out... what kind of a doctor is he... If [they are] good friends, then you trust [them].</p> <p>I'm getting on in years. The thing that perhaps is most important is to find someone who understands geriatrics, because you go to some younger doctor... and he's dealing with ordinary run-of-the-mill type stuff and here you're an old coot... [the doctor] doesn't necessarily know.</p> <p>I think that... if you trust your primary care doctor, he is the one that's going to refer you to the specialist.</p> <p>And when you... [go] from one doctor to the next you get the same mentality, the same type of background and education that the other one had... without getting say an update or a younger person with a more liberal type of approach to an illness.</p>

## MEDICARE HMOS

General population participants expressed mixed feelings about Medicare HMOs. They liked the idea of lower costs and more extensive coverage, but were discouraged by restrictions on provider choice and perceived restrictions on access. Participants noted that their own providers' participation in Medicare managed care would influence their decisions to join an HMO. Participants generally agreed that HCFA could play an important role in explaining how Medicare managed care works and the available options. Participants suggested creating a single source summarizing and comparing the benefits and costs of Medicare alternatives, including both managed care and fee-for-service plans. Participants felt that this kind of resource would go a long way towards relieving the confusion many of them feel as they sort through the large quantities of materials mailed to them by managed care companies.

**HCFA could provide useful information about Medicare options**

Moderator: What kind of information would you like the [Medicare] program to provide?

Participant: How... Medicare would be compatible with the... HMO's... payment and service.

Participant: Chart... at least the HMO companies. A comparison of coverage... straight down where you could look at it and read. A lot of times you would have to go through three or four or five articles... You forget what you have really looked at.

**SUPPLEMENTAL INSURANCE**

For the most part, general population participants' responses to questions about their experiences choosing supplemental insurance divided them into three groups: those who understand Medigap options and how to get information about supplemental insurance; those who are less informed but have trusted sources to whom they have turned for help; and those who are thoroughly confused. It is important to address these varying degrees of knowledge by making information available in a variety of formats and from a broad range of sources. Participants mentioned some specific issues that they would like additional information on, including: insurance rates across companies; information about any restrictions on provider choice; and requirements and/or options for getting a second opinion.

**Diverse experiences selecting supplemental insurance**

I had at least three companies that I was deciding from. I had all the information that I needed. They all send you charts. They tell you precisely what it is. The cost for Plan A through Plan F, I believe it is, or Plan G. These are all Medigap programs... So because the government has said you can only have A through F or G plans to offer, and they're all exactly the same, the only difference is the price. Therefore, the choice is comparatively easy.

A friend of mine whom I trust. He researched my company pretty well and then I checked with my agent and he said it was a very good company and I bought it.

I don't know if I had a choice. I don't know how I got [my supplemental insurance]. I really don't know.

**STAYING HEALTHY**

Most general population participants agreed that they get plenty of information about staying healthy. Some mentioned that they appreciate receiving reminders about preventive care, such as the flu shot notices that periodically accompany Social Security checks. Participants reported having difficulty sorting through competing claims about healthy habits, and they believed that HCFA could address this

information gap. Several respondents were confused by conflicting information about how to stay healthy, while others had trouble reconciling research results with their own experiences.

<b>Potential role for HCFA reconciling conflicting information</b>
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There's a lot of information. I wish there was some governmental agency that would discern which is good and have some [statistics]... on how it comes about.
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## **OTHER INFORMATION NEEDS**

In general, it was difficult for general population participants to respond when asked what information they need but do not currently have access to. Nonetheless, the focus group discussions elicited some suggestions. Beneficiaries asked for the following kinds of more specific information: information to help them track their claims; regular updates on policy and procedure changes in the Medicare program; a list of resources they can turn to for help with commonly asked questions or problems; stricter and more accessible guidelines to follow when they suspect fraud; clear communication about how Medicare is funded; and reassurance about the program's future.

<b>Medicare questions HCFA could answer</b>
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It would be good if we had some sort of list that remains static, that doesn't change, with certain things if you want to call... Where to contact this person, that person, or this agency, that agency. And that doesn't change... [That would] be helpful in connection with trying to locate information.
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Participant: I think it would be a good, an extremely good, idea for... the government to keep us posted, maybe not by the month, but yearly, on the different benefits we can take advantage of or look for with our Medicare coverage.

Participant: I think that would be wonderful... How do you know what the changes are, unless they point it out to you? And I just give up.

My question is where does the money come from for Medicare? I know it's tax money. Is it Social Security? When people pay into Social Security over their working years, isn't that where the money is supposed to come from? It was supposed to be a large amount of money. Then I understood about the end of the 40's they began dipping into the fund for other purposes... That's my only question: Where is the money?

### 3.2 MAJOR FINDINGS FOR BENEFICIARIES WITH LOW EDUCATIONAL ATTAINMENT

As with other beneficiary subgroups, beneficiaries with low educational attainment had a variety of information-seeking preferences. A few of the participants with low educational attainment preferred a high level of involvement with the Medicare program and with Medicare processes. For example, these involved or proactive beneficiaries reported that they wanted detailed information about their Medicare claims so they could track the charges and help Medicare identify errors. Other participants with low educational attainment reported more reactive information seeking preferences — looking for information when they needed it. Many of these more reactive information-seekers reported that they didn't need information about the Medicare program because they haven't had problems with it. Some participants with low educational attainment seemed to rely on passive strategies for gathering information about Medicare. These beneficiaries had basic questions about the Medicare program and their coverage, but they did not report any attempts to get answers.

#### **A variety of information preferences**

##### **Some were proactive information-seekers**

If I'm going to have surgery, or my wife... I'll ask the doctor ahead of time, 'Are you willing to accept the 80% that my policy pays?' before the surgery. If they say, 'No,' then you can stop and think, maybe you need another doctor...

Before you go, you should call and they should be there to explain it to you. You should call... Don't wait until you go to the hospital because when you get to the hospital you may have to come up with a whole lot of money so you need to call and find out what benefits you actually have before you get to the point where you really have to use them. You should have gotten a booklet or something with your card.

Last year when I became 65 years old, I wanted to know what I was getting before I got it. I was wondering if there would be a change and what kind of change would I be getting.... I went down to the social security office and we talked about it... I went to them and told them my birthday and I would be 65 and they told me the difference in my finance and my Medicare and everything else

I've had just all kinds of people all of a sudden take interest to get me signed up for this and that program. I said no, let me just wait until I get better informed about what is going on.

##### **Others were reactive, looking for information when they have a problem**

Whatever Medicare sends, I don't have any problem. Whatever they send me it comes to pass. I don't have any problem.

I really don't understand this because I never had to go for any information

They pretty much took care of theirselves. I didn't have to get information back than what they already gave me.

I think I called them once. And it was in regard to, you know, why there was no payment made. And

basically I learned this pretty quick, that usually when it's filed in the doctor's offices, they use the wrong social security numbers. And that is about 90% of social security's complaints, I mean Medicare's complaints.

I have Medicare A and B, and I don't know which is which, but since I have insurance... any time I go into the doctor's office or hospital... as long as there's that Medicare and the supplement they take care of everything.

I don't worry too much about it, because of the two insurances. One takes care of, you know, so we're pretty well covered, you know, so far... Since we don't have to pay, there's no need to question.

I think probably if we start digging we came up with a medical problem that when we're told that Medicare didn't cover it, then we would start looking for answers, but none of us have encountered that.

## **BASIC PROGRAM INFORMATION**

Few participants with low educational attainment understood how the Medicare program is structured and how the components work together. Others had some basic questions about how the Medicare program works and how they should use it. *At least some beneficiaries with low educational attainment would benefit from more effective information about how the Medicare program is set up and how beneficiaries can use the program to get care. Orientation and introductory materials should include information about enrollment and program qualifications.*

### **Some understood how to use the Medicare program to get care**

Yeah, plus my insurance. See I called—really, I see all the information on my insurance company and they give it to Medicare. And then they pay so much, and they give it back to the insurance company and they pay so much, and give it back to me.

### **Others had basic questions about how the Medicare program works and how their care is covered**

I've had just all kinds of people all of a sudden take interest to get me signed up for this and that program. I said no, let me just wait until I get better informed about what is going on.

The only thing I know is that at 65 you are qualified for certain benefits. What those benefits are, I really don't know. I'm not that informed.

I'm not even familiar with Medicare insurance company.

My problem is really just one thing and that's whatever they feel like they will approve from the doctor, they approve. So they pay 80 percent of it and I'm left with the rest. They don't know if I can afford that 20 percent or not... I'm serious. Because I look at my bill sometimes and I say oh, they don't know if I have this much money or not. What gives them the right to approve it?

I go in the hospital a lot, myself. I got a bill from the hospital that said I owed them \$1,000. Where am I going to get \$1,000 from?

I had been hearing about Medicaid, Medicare. I never could tell which was what.

Could you straighten this out for me? Medicaid and Medicare, what is the difference between these two.

**A few had questions about enrollment and program qualifications**

I'd like to know the qualifications to get it?... I've asked several people and gotten several different answers. I just like to know if there could be a possibility of me getting something that I can use.

**Some knew how to get answers to their Medicare questions**

If you call Medicare, they will explain it to you. Have your papers ready, right there with you and call them and ask them and they are supposed to explain it to you.

I think I called them once. And it was in regard to, you know, why there was no payment made. And basically I learned this pretty quick, that usually when it's filed in the doctor's offices, they use the wrong social security numbers. And that is about 90% of social security's complaints, I mean Medicare's complaints.

I had a bad experience... I was paying the doctor there... and then I would get back a statement where the insurance had paid them. And it happened about four or five times, so I had to call [the insurance company]... and they talked to them. And after about 5 months, I persisted and I got my money back, because they were getting paid by me and from the insurance.

**Several reported that resources were not helpful for the questions they had**

Some people tell me that I'm qualified for it and some people tell me I'm not. I contacted several institutions and things like that. They told me I wasn't qualified, but then I contacted some others and they told me that I was... I've gotten a lot of brochures and things concerning Medicare. But, I've gotten nothing definite yet, whether I qualify or not.

Participants with low educational attainment had some general questions about coverage under the Medicare program. They also had a variety of specific questions about their costs and their coverage.

**Participants had a variety of questions about Medicare costs and coverage**

The only thing I know is that at 65 you are qualified for certain benefits. What those benefits are, I really don't know. I'm not that informed.

I've talked to them several times, but I never mentioned anything like that. I just wanted to know what it was going to pay me... Certain things that they pay me for and certain things they don't. I wondered why they don't and when they don't.

How much do they pay. If they don't pay for hospitalization, you know, how much do I have to pay if I'm in the hospital. That's the sort of thing I have to know.

Well, isn't the only thing that any of us really want to know is are you going to pay for this, or am I going to have to pay for it? What's covered, what isn't.

So just put out a basic book of what's covered in simple language and what isn't covered

I do a little part time job. They take out Medicare. Yet, they still take the Medicare out of my social security. What is this double whammy?



A few participants with low educational attainment preferred detailed involvement in claims processes. These participants wanted claims paperwork and conventions that made claims easier to understand. Also, some participants were interested in receiving current information about potential legislative changes to the Medicare program.

#### **A few preferred to be involved in the claims processes**

Participant: How many people can read a hospital bill and know exactly what everything is on there? I mean, there are so many different names.... And even your secondary supplement... the bill is sent to them automatically. It don't go to you anymore. I've always wondered why, because you could say, 'I didn't do that. I didn't do that. Wait a minute. I wasn't here that day...'

Participant: And when the hospital does send you a bill, it will abbreviate everything in their terms. Who the hell understands it?

Moderator: So how about the rest of you? Would you like to see more information about what processes the claims go through?

Participant: Yeah.

Participant: I think there should be.

Participant: Yeah, that sounds like —

Participant: And put it in laymen terms.

#### **Some wanted details about potential legislative changes to the Medicare program**

Now, this last bill President Clinton signed in reference to balancing the budget, that means they're going to cut Medicare? Do we have to pay more?

## **CHOOSING A PROVIDER**

Participants with low educational attainment mentioned a variety of criteria that might affect provider selection, including education, experience, and interpersonal skills.

#### **A variety of criteria for provider selection**

Participant: First, I need a real doctor. Second, have they been practicing in the US?

Moderator: What do you mean by a real doctor?

Participant: Well, just that. Someone who has the, what school did he go to, whatever. What are their degrees? To what extent is his medical knowledge. If he is familiar with the types of decisions he needs that's necessary for me to have. Has he ever done this before?

I have to have a relationship with the doctor. That's one of the most important things.

If I don't feel free to talk to the doctor about how I feel and things, I'm going to miss a whole lot. So, I think it's important to go with intuition.

I'd love to know but I don't think you can find out if he came out at the top of his class, whether he was in the middle or the bottom.... I want to know about his education, how qualified he is.

His bedside manner.

And most of all, can you trust him?... Until you know them you're not going to know that.

Participants reported relying on recommendations from friends and family for choosing a provider. They also mentioned referral lines and referrals from other providers.

**Participants mentioned several sources for provider selection**

You can go to the AMA. They have a lot, and hospitals have ...places that you can get information about the doctors

I have a doctor referral. There's a place you can call and they tell you how many years he's been in practice and things like that.

I chose based on a referral from a good friend.

Well, I have a... doctor that I have almost complete trust in... And he knows enough people that if I need a specialist or something, he would be the one I would ask.

Through a doctor's referral or a friend.

I think I would go through my doctor's referral or health plan.... It's because I trust the doctor.

Most of us go by family and friends, somebody recommends a doctor. Otherwise, where are you going to get information about a doctor?

*A few participants with low educational attainment said that they would like to receive information from HCFA to help them find and select providers, but others were not sure that government was a good source for information about providers.*

**Some said it is difficult to get useful information about providers: Information from HCFA would be helpful**

With us, we've got to feel our way, make mistakes.

Sometimes you just can't get the information that you need.

Participant: Well, if you call the hospital, they do. They have that referral.

Participant: Well, but when you get an organization, any hospital will prefer their own doctors. Do you follow me. And probably the HCFA will refer some of the doctors from this hospital, but when you get it from the horse's mouth, such as HCFA, which is a government [agency] that's running Medicare... everything goes back to them. They will recommend top notch.

Participant: I'd rather trust an individual than the government.

Moderator: Do you think that that's something that the Health Care Financing Administration or Medicare could help you out with? Would you like information from them about doctors or specialists?

Participant: I think so.

Participant: It would be helpful.

Participant: It wouldn't hurt.

## MEDICARE HMOS

Some participants with low educational attainment had questions about how HMOs work and how they fit with the Medicare program.

### **Some had questions about HMOs and how they fit with Medicare**

Where does this HMO come from in here?

I would imagine everybody here understands that when you have HMO, HMO is your main supplier and Medicare is your supplement. I would imagine all you people know that.

I would like to find out more about this HMO.

They also expressed concerns about Medicare HMOs, including concerns about quality of care, access to care, and provider choice.

### **Questions and concerns about Medicare HMOs**

#### **Quality of Care:**

Are these HMO's and all that, are they legit? I mean that, because I hear so many things you know, that this one HMO did this and wasn't supposed to ... was involved in this kind of scam, you know.

If a person goes into a hospital that's on the HMO list, do they have a certain hospital you can go to and certain ones you can't?... The hospitals that you can go to, under HMO, are they second class hospitals?

#### **Access to Care:**

On an HMO policy, a doctor is paid X amount of dollars a month or per year for you, and this is it. When you get close to the end of that part of money, say at the end of the month, and say you're not satisfied with the care you're getting and you tell the doctor, 'I want to go see a specialist,'... if the bill is X amount of dollars and you only have X amount of dollars left, the doctor has to pay that excess amount out of his pocket. He's certainly not going to do it.

Let me ask you a question. If you have any kind of an HMO, do you have to get referrals to go to the specialist?

I had a friend that had cancer and she went to this hospital and do you know they did not take her. She had that HMO and they would not take care and she had to be referred to another hospital. I mean I have asthma, too. Now I'm thinking way in the middle of that maybe I can't breathe, now I can't go to that hospital but that might be the closest one to me. All right, I'm having an emergency here and they're not going to wait on me?

#### **Provider Choice:**

And then, too, they say that you can't have your own doctor. You have to use the doctors they assign you to or the hospitals or whatever that they assign you to.

For one reason, you can't choose your own doctors.

I just stayed with Medicare, because I have gone to this doctor for years... And I hate to give him up. I hate to go to a new doctor.

Some low education participants mentioned receiving information about HMOs from HMO companies, either through the mail, or through presentations made by company representatives. Friends and family members were also important sources of information for these participants.

#### **Information from HMO companies**

They will send someone to talk. They will explain it to you if you call.

I've sat in on some of their promotion sessions, about three of them at least because every so often they'll come to the center.

I go to a senior citizens center and they come to the centers to make their presentations and I would just, you know, gather information.

Well, I get literature in the mail about them, you know. They have meetings and want you to come and attend so they can explain it to you...

Moderator: So where did this information come from?

Participant: The mail.

Moderator: You got it through the mail.

Participant: Well, they call you and ask you to come to meetings, you know.

Participant: They send you literature, too, all the time.

#### **Family and friends are also sources of information about HMOs**

My children are on an HMO and they don't seem to have any problem. Because, well, you do have to have doctors within their program, but they have very good doctors... I do know they have to have a referral from a doctor to go to another place or whatever but it doesn't seem to bother them.

I have friends that's HMO and through what they get, I don't care for it.

But my husband, he likes it. He likes all the doctors that they send him to. And they have really done good work and everything, but I'm just a little bit afraid to step over...

## SUPPLEMENTAL INSURANCE

Some participants with low educational attainment understood the structure of supplemental plans available to them. Other participants lacked basic information about the insurance they had.

### Some understood supplemental plans

I'm saying like for AARP, when you go from A to J or H, whatever, under those different plans, you go for the prescription drug, it's outrageous, the premium, right?

Moderator: So do you feel as though you had enough information about the supplementary insurance to make a good choice, or was there other information that you would have liked to have had to make this choice?

Participant: They're all identical.

Participant: Pretty much so.

Participant: They all are identical. Not one goes any step further than the other, unless you go into another step of it, you know.

Participant: There's little differences in premiums, okay. The premiums vary so little... unless you went to the next step up... you know, like prescriptions... but basically they are all the same, with the exception of little differences in premiums.

Participant: I would think prescriptions would be worth a little higher premium.

Participant: Well, you have the option of purchasing it.

Participant: Yeah, they're expensive.

### Some lacked basic information

I also have catastrophic. What is catastrophic? I have it but I don't know what it means.

Many low education participants agreed that selecting a supplemental plan was a complicated and difficult choice. *Participants wanted simple and objective information about the plans, including plan comparisons. They thought HCFA could be a good source for information comparing supplemental plans and options. Also, some participants wanted guidance or advice from an objective source such as HCFA.*

### Supplemental insurance is a difficult choice

It's still very difficult to try to figure out what's going to happen. And there's no agency that tells you.

Moderator: Do you feel like you had enough information about different plans available to you?

Participant: Yeah, but it's hard to try to figure out which one is the best for you.

### Part of the difficulty stems from problems anticipating future needs

My husband was the one who made the choice and it's been okay, it's been fine. A lot of it is based on the cost as well as what the benefits are. Sometimes you pay more and get more benefits. You pay less and get less. You just kind of have to make a guess at which is the better one.

If we could foresee into the future, many of us would do things a lot different.

**Some useful information from supplemental insurance companies**

When you go down to sign up that you're retiring, they sell that list to every insurance agency in the country. They flood your mail with that sort of information.

When I signed up the guy came up and sat down and explained it to me and told me about it and everything and then he brought in more and I got a better understanding of what was covered and what wasn't. But I mean I don't have any problem out of those people at all.

Moderator: Do you feel like you had enough information to make the choice you made?

Participant: Yes, I think so.

Moderator: Where did it come from, do you remember?

Participant: Well, I contacted them and the representative came out and talked to me, explained Medicare and everything on it.

**General agreement that available information is too complicated**

It's very difficult to try and figure out what is the cheapest secondary insurance that you can have and what's covered. And really, there isn't any information that comes from the government, except to say you have a choice of A, B, C and D. But it really — it's very difficult to set them down and try to figure out which one is compatible.

Participant: It's very difficult to understand.

Participant: It's very difficult.

Participant: Me, too.

I don't care how much any of us really read into it, and I read it quite a bit. And sometimes I have to read it two, three, four times before I even get a little grasp of it. It's ridiculous that they can't, you know, they can't make it simple.

**Participants want objective information to help them make comparisons**

I get brochures from AARP. I get brochures from a few other places.... I get quite a few brochures. And everybody is promoting their own programs.

You really don't know. You have no knowledgeable thing that says this gives you this better than this.

**Participants would like guidance from HCFA**

Well, the way they're written. It says, 'We are forced by the federal government to offer you A, B, D, E, and G,' but when you start reading over them and figure out what they do for you and then look at another policy and try to figure out what that's going to do for you... So it's very hard to figure it out. And the federal government don't give you any leeway or any guide in that book to say, 'Hey this is what we found out through our legal opinions or whatever,' and we had no guidance.

If anybody should give us pertinent, honest information, it should be Medicare, because Medicare is the one that would gain the most in the long run.

## STAYING HEALTHY

Participants with low educational attainment identified a variety of sources for information on ways to stay healthy, including health care providers and the media. Some thought that the volumes of information available made it confusing. A few thought government should not get involved in providing this kind of information.

## **Variety of sources for information about staying healthy**

### **Health Care Providers:**

I think it is being done in the clinics... I prefer to go to clinics.... The clinics have board members consisting of the patients. They can participate in monthly meetings concerning the doctors, the nurses and the treatment that they receive. They also can secure the information that is more valuable than the newspapers and TV that can assist you healthwise.

Whatever you do don't ask the doctor.

Moderator: Well, who would you like providing that information to you, about how to stay healthy? Who would you want to hear that information from?

Participant: My own personal doctor.

Moderator: How about information about ways to stay healthy, where do you go to get that?

Participant: A nutritionist.

Participant: Your doctor.

Right. I think you can find enough literature in your doctor's office.

### **Media**

I hear a lot on television...

Oh you see it on TV about where they will be giving flu shots and the clinics. It also comes from Medicare too.

TV.... I think that informs you. They tell you where you can go and get free pneumonia shots.... flu shots. They tell women where they can go have a mammography....

### **Senior Housing:**

Usually where you live has a lot to do with the amount of information you get. If you live like in certain high rise where there are elderly, strictly elderly, then usually there's quite a few agencies that come in there and give you that information. There are bulletin boards, articles.

I know in my complex, they had a group of people that came in and they asked all the tenants to bring their medications. They examined the medications and determined whether or not it was good to have generic or.... They also determined whether you were taking medications that could work against you and duplication of medicines. That was very good.

## **The large amount of information is confusing**

Participant: Everywhere. TV, radio, newspapers. I mean they pound it in you, every day, every minute of the hour. It's confusing. You don't know what's right or wrong.

Participant: Very conflicting information.

**Concern about information from commercial sources**

Some of that information is very good, but then you also have to consider the fact that they are trying to sell the medication.

I think it's a truth in advertisement issue... How many TV programs have you watched that said, 'Ladies get this and you got to have some fun. It will cost \$600.' Next thing you see is they're spending a billion dollars on cold medicine.... Take zinc. Take vitamin C. Then that night at 6:00, here comes the doctor on. Don't use vitamin C. You're wasting your money. There's no truth in advertising.

You sit there and you listen to it and you say, 'I don't know. Where can I get the true, real information from about whether a food, or whatever,' just like you're asking....

**A few participants thought government should not get involved in providing information on staying healthy**

And we don't really have to be directed by some government agency or somebody else what is food, what to eat, what not to eat.

## OTHER INFORMATION NEEDS

Participants with low educational attainment identified a few additional information needs. One participant wanted more information about individuals' contributions for Medicare, and several participants wanted reassurances about the future of the Medicare program. Other participants highlighted their need for simple information presented in a way that is understandable.

**Information about the future of the Medicare program**

I read a lot of stuff, you know, about the controversies. You hear something about this program and it's run amok and that [Medicare] has gone ballistic and social security is about to be demolished. All this kind of stuff.

Participant: I would like to really know for sure if Medicare is in as bad a shape financially as it's advertised to be....

Participant: Yeah, you know, at our age, you know, it would be nice to know, you know, am I facing a crisis here, and not having financial aid.

**Preference for simple, understandable information**

I would like it to be more simplified.... So, like she said... she read it, but really she could not grasp everything about it. When I read something, I want to understand it. I want to know what they're trying to tell me, what they're saying.



### **3.3 MAJOR FINDINGS FOR BENEFICIARIES WITH HEARING LOSS**

The moderator's guide for focus groups with beneficiaries who had hearing loss differed from the general moderator's guide used with most other beneficiary subgroups. For beneficiaries with hearing loss, we were particularly interested in their preferred information sources and their reactions to alternative media. Therefore, focus group participants with hearing loss spent less time talking about topics directly related to their information needs compared with other beneficiary subgroups, and relatively more time talking about topics directly related to alternative information sources and communication media.

As with other beneficiary subgroups, beneficiaries with hearing loss varied considerably in their information-seeking preferences. Some participants with hearing loss prefer a high level of involvement with Medicare and Medicare processes. These beneficiaries indicated that they want detailed information about their Medicare claims so they can track the care they receive from Medicare and identify errors. Other beneficiaries with hearing loss prefer specific information. These beneficiaries tend to seek information when they need it to answer specific questions. They want to go directly to a source that is trained or has the experience to answer their questions. They do not want to have to filter through a lot of extraneous or immediately unnecessary information to get the specific information they are looking for. A third set of beneficiaries with hearing loss said that they don't need additional information about Medicare because the system works smoothly for them.

## **A variety of information preferences**

### **Some preferred active involvement**

I know people that don't even read the forms that come through Medicare... And I have picked up in the past several instances where the doctor, not intentionally, charged wrong. In one case they were charging me for a visit that I had cancelled... This is some clerk in the doctor's office, who pushed it through. Medicare had approved it and paid. And when it came to me and I got my bill, because I went right after that, I informed the doctor and I informed Medicare, because I consider that very serious. So if we're more informed, we can do better in helping them to get costs down. But they got to explain it to us...

### **Some preferred to receive specific information when they need it**

I'll tell you, man. I don't want to have to research any answers to Medicare. They got a little red book, white book down there. That's not for me. I want somebody to give me an answer, you know, without me doing all that work.

Medicare never puts a TTY number on its papers. And so I have to rustle around and find it.

### **Some said they don't need information: Either the system works smoothly or Medicare's involvement is transparent**

I'm the odd ball in this situation.. Everything has gone smoothly. In the six years I've been retired, I've had three hospital visits... I go to hearing—ear doctor. And, of course, I have my regular family doctor, but everything's been taken care of. I have not had to call Medicare about anything...

Moderator: You haven't needed to.

Participant: No... the paperwork has been sent in. I get the statements back with what I have to pay, the difference... I submit it to them. It's all been a very smooth thing.

Moderator: Okay, but how have you known what to do?

Participant: Well, when I first retired I applied for my Social Security. And they gave me a booklet on Medicare, and my card. And I've given the number on all these occasions and it's all been smooth for me, so far...

Participant: I just want to say that my case is the ... the papers come in, and I send them in and they send me a check. I understand what they're doing, mostly.

Moderator: ...So, basically, the majority of you here have not needed a lot of extra information because things have gone smoothly.

I get this literature in the mail from AARP and different organizations. I just toss it aside... because I'm retired military. I go to a military hospital for my treatment. And then the agreement is, my primary insurance has agreed with the military to pick up the tab, based upon what they are willing to pay. So I've never been exposed to Medicare.

Well, we've never had problems with Medicare... it's come through... and no complaints. We use it for many other things.

## BASIC INFORMATION

Participants with hearing loss had relatively few basic questions about the relations between the Medicare program, the insurance companies who pay Medicare claims, and supplemental insurers, compared with general population beneficiaries. Participants with hearing loss were recruited through a hearing loss consumer organization, and so the lack of basic questions may reflect how active involvement with consumer groups can contribute to knowledge of the Medicare program. A few participants with hearing loss had questions about the relationship between Medicare and their primary payer that were related to their own relatively complicated circumstances. Others seemed to have clear understandings of their complicated situations.

<b>Some had questions about complicated insurance situations</b>
When this is—one question I wanted to raise, that some of us may have rather convoluted health insurance situations, because I do, because I spent all of my career in the civil service. I am not automatically eligible for Medicare. So I have to pay and do a different thing. And it's more complicated. And sometimes people don't know which way it is supposed to go, whether to Blue Cross or Medicare.
<b>Others understood their complicated situations</b>
Because I am not normally eligible for Medicare, never having been under Social Security, I have to buy into Medicare B, which is outpatient. I do not have Medicare A, because I'm getting more from my government federal employees insurance, even though that's secondary.

One participant said that she would like to receive some simple and very basic information about the Medicare program because she has always counted on her husband to manage their coverage, and she realizes that she will soon need to manage on her own.

<b>Basic information needs: Can't continue to rely on someone else</b>
Participant: My question is, my husband's condition is such that I don't think he'll be around for, maybe after two years, so what I would like to have from Medicare, if they have any kind of information for dummies, when you're first just starting out. I've seen so many widows just being overwhelmed with handling this stuff the first time.
Moderator: So you're talking about information presented very simply and very easy to understand.

Participants with hearing loss had questions about their coverage under Medicare. Many of these questions were similar to those raised by focus group participants from the general beneficiary population. For example, participants had questions about Medicare coverage for preventive dental care.

### **General questions about Medicare coverage**

We proceed on the assumption that Medicare covers all of our needs. And the only time a problem comes up, it's either [of] two ways. One is when the doctor tells us, or a consultant tells us, that this procedure is not covered and you're going to have to pay for it yourself... The second one is when we receive from Medicare the explanation of benefits where they deny part of the doctor's bill which means it's going to fall on us. And then we have to go out and start our inquiries... But we all proceed on the assumption that we are covered. That's the start.

Participant: Last summer I had an accident.... And it meant a lot of dentistry... I was told that Medicare would not touch it.... They would not pay the repair work on the tooth itself. And so I had to finance all that myself. And nobody had any information on it.

Participant: Does Medicare cover dental work?

My mother was ill and was in a nursing home. And I thought she could be covered under Medicare. And I was told that she needed only custodial care, which Medicare would not pay for. Only if she required skilled nursing care would Medicare pay for it.

The only reason I call them is to find out whether a procedure is covered by the Medicare: if they would pay, reimburse me or pay the doctor.

It had to do with mammograms... And she had a very hard time understanding, I guess they only pay for mammograms every two years... Yet in one case they paid for mammograms and then they didn't pay the doctor reading the mammograms. And the next year she had it done again on the advice of a doctor and they paid for the doctor reading that mammogram but wouldn't pay for the mammogram.

It would be nice if Medicare covered some of these preventive measures for health care... what they call a good physical. Even if they covered 50% of the cost... It would help. More people would go and have it done once a year.

Participants had a few questions about coverage that were specifically related to their hearing loss. Some participants wanted information about why Medicare does not cover hearing aids. Other participants noted that it is important for beneficiaries with hearing loss to realize that Medicare covers some kinds of hearing-related care.

### **Questions about coverage related to hearing loss**

One thing that we haven't discussed at all, which was one of the reasons for this meeting, I thought, was the fact that Medicare does not pay for hearing aids.

My audiologist, when I went for my hearing aids, told me that if I would go to my doctor to get the prescription... to have your hearing reevaluated, Medicare picks that up, that hearing test which is \$85. Now, he did inform me of that, I didn't know it.

I would like to have some information why does not Medicare pay for some people's hearing aids. They pay for those roll-around chairs and they pay for the chairs that lift you up off the floor to make you stand up but there are a lot of people that really, especially in nursing homes, they can't afford hearing aids. And why can't they pay some on those?

Participants with hearing loss had questions about claims and claims processes that were similar to questions raised by general population beneficiaries.

<b>Questions about claims and claims processes</b>
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Apparently they didn't put the correct number, a complete number [on the submitted claim]...My question is, why, since it was obviously sent to Medicare and wasn't complete, why didn't they send the papers back to the doctor's office right away so they could correct it and send it back? I waited almost six months before I was partially reimbursed.
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I've tried to get information about the amount that Medicare paid a hospital and I found it frustrating because they wouldn't tell me on the phone... And we had a conflict in the amount that Medicare had paid the hospital based on the out-patient, but it was billed under the regular — not the physicians, but the hospital.
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I feel that we are completely confused about what is covered and what isn't... every year she goes for a check-up and Medicare is supposed to pay it. But last year they wouldn't pay the physical examination that she has to take every year in order to determine whether the cancer has returned. So, but now, it's been a whole year that we're trying to, we paid the bill but we're trying to get it straightened out with Medicare and so far, it's just been one delay after another.
--

Participants with hearing loss were similar to the general population beneficiaries in another way. Both groups of participants asked for information on recent changes to the Medicare program. Participants with hearing loss said that they would like to receive regular information about program changes.

<b>Updates and changes in Medicare program</b>
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Participant: I've been with Medicare now, heavens, 15 or 16 years. I've had [some information] in between updating it, but I haven't had anything that recent. And there are a lot of changes, I've discovered.
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Moderator: So you feel like you need to be updated more regularly.
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Participant: Yeah...
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There have been some changes that I was not aware of.
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Listening to [her], I'm thinking, I realize that I had some updated information, but I haven't had anything recently either. And I'm curious, you know, when there's something coming.
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Procedures for reporting suspected Medicare fraud is another question raised by participants with hearing loss that was also important to participants in the general population focus groups.

<b>Medicare fraud</b>
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To whom do we complain about Medicare's being, uh, uh, fraudulently handled by hospitals?... I reported it to the hospital but I did not call Medicare and I should have.
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In summary, the questions about the Medicare program that were identified by participants with hearing loss were often similar to questions raised by general population beneficiaries. *Beneficiaries with hearing loss would benefit from specific information about hearing care that is covered and hearing care that is not covered under Medicare. They also asked for information about why Medicare does not cover hearing aids.*

## CHOOSING A PROVIDER

Like general population beneficiaries, participants with hearing loss reported that family, friends, and other providers are useful resources when looking for a new primary care provider.

<b>Advice from family and friends and from other doctors</b>
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I usually ask a friend for a recommendation.
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I suppose I would talk with family members and speak with friends.
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First through family and friends... it starts with family and friends.
--

I prefer to ask another health person, employee, like a nurse, to me is more honest than if you find out through professional leads.
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Participants mentioned other resources for finding new primary care providers, including group practices, hospital referral lists and other professional listings.

### **Other resources for primary care providers**

#### **Group Practices:**

Well, we've been here quite a while, and depend on friends. My doctor retired, and so his practice went to a new doctor. And we are satisfied with that doctor. So we stayed with it.

First through family and friends, but then the doctors belong to group[s]. And one doctor—sometimes you will meet one doctor or another and find one that you prefer in the group... But it starts with family and friends.

#### **Hospital Referral Lists:**

I noticed that [a hospital] often sends notices out if you need a doctor for specific things. You can call the hospital and they will recommend specific doctors for a specific illness.

If I were a new person in town, I think it would be hard unless you went through a hospital.

#### **Professional Listings:**

I go to the library and look up the directory of medical specialists that will tell you which doctors in which states specialize in what particular type of medicine.

But there have been occasions when I called the County Medical Society and explained what area I wanted to find a specialist in.... the medical area. And they would give me several names and the background, the training of those people.

Participant: I don't know if we get enough information... There again, my wife gets a book every year that lists all the doctors in the areas.

Moderator: Okay. What information does it give you about them?

Participant: It tells you what field they specialize in and what their location is with their telephone numbers. Also we have... an Ask-A-Nurse program where we call the nurse... and she'll give you any information regarding doctors.

Some participants with hearing loss reported that the information they need to make an informed choice about a new primary care provider is not easily available.

### **Information needed to evaluate primary care providers is not available**

We don't really have available the information you want... [the] medical school he went to, were there any cases pending against him for malpractice, how long he's practicing, size of his group of patients. That information is available if we dig but it's not readily available. It's not easy. We have to go searching for it.

If our internist gives us the name of three doctors, which one do we take? There is no source that I know of readily where you can read about that doctor and know all about his experience of what he's done, his standing in the medical community.

If you call a hospital, they'll give you a list of doctors but all they're giving you is a list.... They're not saying this one is good and this one isn't. It's 'here's five cardiologists that we use, take your pick.'

Participants reported relying on referrals from other providers when looking for a specialist. Participants mentioned few other resources for finding a specialist, and a few participants reported that they wouldn't know where to turn if they didn't like a specialist identified by their primary care provider.

<b>Recommendations and referrals from other providers are good resources for specialists</b>
<p>But a recommendation, I guess, is the best thing.</p> <p>Participant: When I needed a hip replacement my medical doctor recommended somebody. And now, with my leg, the acupuncture, he also recommended somebody... I haven't had to find it through a list or something like that....</p> <p>Moderator: Okay. And you're happy with getting like that. You don't feel like you need to go somewhere else to get the information?</p> <p>Participant: No, I've been satisfied.</p> <p>Most of our—all of our referrals have come through our family doctor.</p> <p>And when I've needed a surgeon or various other things, or specialist, my primary care doctor recommends them, and it seems very satisfactory.</p> <p>You don't have to go looking. Your internist could tell you, if you have a skin problem, see this and this doctor. If you have a pulmonary problem, he'll send you to [another doctor]... You'll have to ask yourself later on, is this the best one available for me? Or do I like him? But you don't have to go looking. Your doctor always recommends someone.</p> <p>You have to put a lot of faith in your primary physician.</p>
<b>Other sources for specialists</b>
<p><b>Hospital lists:</b> On a major case, where I needed major surgery, I had several recommendations. And we check out with—this was hospital service.</p> <p><b>Friends and family:</b> I would prefer hearing word of mouth, someone who, a friend of mine who knew, you know, the specific doctor.</p>
<b>Some were not sure what to do if provider referrals don't work</b>
<p>After my first doctor was recommended, that I was very unhappy with, and I wasn't doing too much, my wife got the yellow pages out and picked someone.</p>

Participants with hearing loss mentioned some specific concerns related to finding new hearing specialists. Participants noted that people experiencing new hearing loss are likely to lack basic information about their options. Primary care providers are often not sufficiently trained in hearing loss to be helpful as patients identify their options.



**Difficulties finding hearing specialists: Need for basic information about options**

I think people who are just beginning... many senior citizens who really are not helped... They are sold instruments [hearing aids]. And the instruments—and they pay \$1,200 for one instrument and it sits on their bureau, or in their bureau drawer.

I think that's the most difficult. Not those [who are] used to going to [a hearing specialist], but the person that's [just] getting a hearing loss. I mean, getting help for a hearing loss. Where can they go?

This is where I like long visits with an audiologist. He did not sell the hearing aid and that made it just super because he recommended what was best for my type of loss.

First, they need to see a doctor. Then they need to go to an audiologist.

You really should get a medical work-up before anybody gets into any sort of assisted devices or hearing aids.

I think it's very hard. My medical doctor... recommended an audiologist and he turned out to be a real disaster for me. I actually was fitted for the wrong kind of hearing aids and I couldn't hear. I actually ended up throwing my hearing aids away... It cost me fourteen hundred dollars. And that came from my medical doctor... I mean, they're not really informed either about hearing loss.

Participants with hearing loss noted that providers' listening and communication skills are particularly important to patients with hearing loss.

**Providers' communication skills are particularly important to patients with hearing loss**

A cardiologist, who sat with me for four hours in emergency care because he listened to me when he did a cardiogram. And I always mention his name. When I was going to have a cardiogram taken by him, he asked me if I would like to come to his office to learn what a cardiograph was... So I went to his office and he told me all the things I might... expect... He said, 'when I say, cough, I want you to cough hard.' And I said, 'Doctor, if you have a mask on your face, I will have no idea of what you are telling me.' And I noticed he wrote something down... The following day when I had the exam, when it came to the part, cough, and cough hard, there was a nurse on either side of me, holding up a sign. Now, there was a doctor who listened.

Participants with hearing loss had mixed reactions in discussing potential roles for HCFA providing information or assistance in provider selection. Some participants believed that HCFA and the government should not get involved in provider selection because of the potential role of politics and commercial interests. Other participants said they might be more inclined to trust information provided by a government agency.

**Some said government should not get involved in provider selection**

In Medicare... if you get those people involved in recommending what doctor you go to, how do they know? That's one thing I think the government should stay clear of. Has anybody ever called [these referral lines]?... They pay for that, to get their name on there. They pay for that... They're paying... to get their name on their list, because they're incompetent.

I agree... I don't want Medicare to be choosing my doctor.

Participant: Because I think if you hear from other patients, you're going to hear more honest.

Moderator: Would you trust Medicare to give you that information?

Participant: Not unless they've experienced having something to do with that physician personally.

**Others thought HCFA could play a useful role in information about providers**

And it would be nice if we had a service like that with Medicare... Your friend will tell you that doctor so-and-so was wonderful. Well, maybe [that provider has] personality, real cute, real nice guy and so on, but do you know whether he's medically competent? That's the problem with this business of going to friends and relatives for a doctor. Oh, they like them. I like my doctor, but my daughter is saying he's a quack.

Participant: If our internist gives us the name of three doctors, which one do we take? There is no source that I know of readily where you can read about that doctor and know all about his experience of what he's done, his standing in the medical community.

Moderator: Uh-huh, but if, if that information was available and gives you all the details of the doctor, would you read it and would you educate yourself and then make your own decision between, say, three doctors?

Participant: Absolutely.

Moderator: You would take the time to do that?

Participant: I wish they had a win-loss record.

In summary, beneficiaries with hearing loss are similar to general population beneficiaries in their reliance on friends and family as resources for identifying new primary care providers and on primary care providers for identifying new specialists. Like beneficiaries from the general population, beneficiaries with hearing loss had mixed reactions to government information about providers. *It seems that beneficiaries would be receptive to information from HCFA on provider selection criteria and referral sources, but it will be important to address likely concerns about political and financial interests.*

Beneficiaries with hearing loss have special needs when it comes to identifying hearing specialists. Some participants believe that primary care providers do not have sufficient background to help their patients identify their options as they face new hearing loss. *There may be a role for HCFA helping beneficiaries to identify options and next steps when new hearing losses are identified. In this area, partnerships with hearing loss consumer organizations could be particularly valuable.*

## MEDICARE HMOS

The moderator's guide for focus groups with beneficiaries with hearing loss did not include discussion of Medicare HMOs, and the topic did not generate any spontaneous discussion in these groups.

## SUPPLEMENTAL INSURANCE

Among participants with hearing loss, most agreed that they had enough information about their supplemental insurance options to make an informed choice. Several participants mentioned types of information they had access to that were particularly helpful to them. For example, one participant mentioned consulting services provided by volunteers at a local health cooperative. Another mentioned comparison charts that she thought she received from the Medicare program.

### **General agreement there is enough information about supplemental insurance**

The information is available, but I have—frankly I haven't really read it, because I've been happy with what I have and I didn't want to change.

Moderator: And do you feel like you had enough information about all those choices?

Participant: Yes.

Moderator: Were the plans spelled out clearly enough for you? Could you understand the different plans?

Participant: Uh-huh.

### **A few mentioned information that was especially useful**

Participant: When I was choosing a Medigap program, I went to [a senior health cooperative]... I took an hour or an hour and a half with a woman who went through all the things that I had and made telephone calls and checked everything and who showed me what the possibilities were and I was able to choose what I wanted...

Moderator: Was it easy for you to be able to choose? I mean, was the information clear that you understood it?

Participant: Yes... She was a volunteer and she knew all about insurance. She was very clear and very helpful.

Moderator: Did you get enough information to make those choices, do you think? Were you clear about what was available?

Participant: That's listed in that Medicare handbook — a comparison. And also prices.

Although there was a general consensus that they received enough information about supplemental insurance options, a few participants reported that they weren't sure they were getting good value for the money they spend on supplemental insurance. *These comments suggest that beneficiaries would like information designed to help them identify good insurance values. For example, HCFA could*

*develop tools to help beneficiaries keep track of their supplemental insurance costs and the supplemental benefits they receive. These tools would be particularly useful if they provide guidance to beneficiaries interested in assessing the value they could expect under alternative supplemental plans.*

**Is supplemental coverage worth the cost?**

I've gotten to the point where I'm not sure what I'm paying on a monthly premium I'm getting back... Because I could be laying out \$200 a month for a premium for my wife and I, and maybe that month what I get back from the 20% from the doctor visit comes to maybe \$20 or \$30.

We wanted to see if we wanted to change it, and we also aren't sure that it's worth what we paid.

Participants with hearing loss generally agreed that they prefer to receive written information about their supplemental insurance options. Participants noted that written information reduces miscommunication and misinterpretation. Participants mentioned receiving information and assistance by telephone, but they said they mistrust information that is not provided in writing. This mistrust seems to reflect participants' perceptions of insurance companies' financial interests.

**Participants prefer written information about supplemental insurance costs and coverage.**

We have AARP. And we have a notice... that they have a new offer that gave you much more. So my husband, who is great for detail, contacted AARP directly and asked for information, written, to be sent to him. And while we pay, I think, a ridiculous amount every three months... their new offer, which they did not tell him on the telephone, would cost much more... Oh, I'm afraid to say how much more but a great deal more, the new offer was, which they never mentioned on the telephone. But when he asked for prices and all, to be written in a letter, they did. So then we did not take their offer.

By far they didn't tell us everything on the telephone... You have to get back-up information and he preferred to see it in writing... So they couldn't say that he misunderstood.

You have to get it in writing in order to be sure.

## **STAYING HEALTHY**

In general, participants with hearing loss agreed that they get plenty of information about things they can do to stay healthy. Several participants noted that they receive conflicting advice or advice that changes over time. Difficulties interpreting conflicting information may be one reason that a few beneficiaries said they get too much information about ways to stay healthy. Participants also said they were suspicious of information from organizations with commercial interests. All of these findings are similar to results from focus groups with general population beneficiaries.

**Plenty of information about staying healthy**

I get the Harvard Health newsletter regularly, once a month. And that's interesting and useful... I also get in the mail about every other week some other university's health letter, what they're advertising. So there's plenty of information.

There's plenty of information... in the print that's out there. Everybody puts out a newsletter now. Every big university, every big health center, hospital, whatever. So there's no lack of information.

There is so much in the newspaper about it constantly, I don't know how you can miss it... The point I'm really making is, the information is out there. I don't see how you can miss it...

**Conflicting information**

It seems like every time you pick up the newspaper or a magazine there's always articles on what you should eat and what you shouldn't eat. Sometimes it conflicts... You got to be careful. They come out with this month something they recommend. Six months later another study says, no, you should do something else. But you can read between the lines.

The funny part of it is, they will tell you at one point in time, don't eat this or don't eat that, it'll kill you. And then two months down the road, they'll say, that's fine, you can eat that. You know, it was the same thing with eggs and shrimp.

Participant: They change so much. It's such a discussion on, what's healthy food and what isn't. And what you can eat and not, it's tough.

**There is too much information about staying healthy**

I feel I get too much information! I have it all the time, coming from magazines... I can't handle them all... Too much from the information comes with a commercial tinge.

And what I would like to see is something that's a bit condensed, that would be a good guideline to follow.

But she's absolutely right, we are inundated with information about what foods to eat.

Like general population beneficiaries, participants with hearing loss generally agreed that their primary care providers are good sources of information about things to do to stay healthy. They identified a variety of other sources including references that focus on particular conditions, health newsletters, the mass media and community resources such as senior centers. All of these sources are general resources. None were specific to hearing loss.

### **Providers are good sources of information on staying healthy**

I get it from my doctor... Well, he'll tell me, when I go for my check up, if I'm doing alright or I'm not. If I should cut out on certain foods or something, while I'm there, he'll tell me. I get my information from him.

I got a pneumonia shot, too. And it's from my doctor tells me I should do this each year and also that I should have a mammogram every year.

As I said earlier, we as individuals don't need the TV to tell us how to be healthy, how to take care of your children, how to exercise, how to do everything... That's the last place to go, because they just have some individual that does it. It doesn't mean he or she has any real experience or knowledge... If we need help, we should go to the professionals. If you need help in nutrition... get it from your doctor or call your insurance company, because they have a concern and they will help you.

Moderator: Okay. What do you think you really go by?... Who do you follow?

Participant: My doctor.

Participant: My doctor

Participant: I usually follow my primary physician.

I think first you get the information from the media and then you ask your doctor about it when you see him.

### **Other sources for information on staying healthy**

#### **References:**

Participant: And I've recently found out that I have arthritis. And so I went to... the book store and I bought three books. And I'm reading them, because I really wanted the specific information. I wanted to be able to underline it and go back to it.

Moderator: Okay. So you wanted to be able to keep it as a reference.

Participant: Right.

#### **Newsletters:**

Participant: Some of the hospitals or community colleges send out regular monthly newsletters, especially hospitals. And they will have different—and they will list their groups, support groups, that they have that you can attend, hospitals and community colleges....

Moderator: And it's been helpful?

Participant: Yes. It is, especially support groups, because I really am in favor of them.

I get the Harvard Health newsletter regularly, once a month. And that's interesting and useful... I also get in the mail about every other week some other university's health letter, what they're advertising. So there's plenty of information.

#### **Media:**

Well, we get a lot from the [local newspaper's] health section.... particularly things on nutrition, and so on, exercise and what have you.

They have it on television. They have it on radio, but they surely do have it in newspapers, magazines, everywhere.

In our newspaper, we have a section called Feeling Fit which they publish, I guess, about every week.

#### **Community Resources:**

[A local senior center] has the heart, cancer and all. They have a certain time...where they have somebody come and talk about it. And you can ask them questions and things like that, to keep your health up.

A few participants with hearing loss noted that they would prefer to get information on ways to stay healthy from sources other than the Medicare program. *There may be a role for HCFA in helping beneficiaries weigh conflicting information about ways to stay healthy, but beneficiaries may be more receptive if this information is provided through information partnerships that involve providers.*

**Some prefer information about staying healthy from someone other than the Medicare program**

Participant: I think, getting back to Medicare, Medicare ought to stick to people and their health, as far as doctors and the hospitals are concerned. That's a big enough problem, and not be getting into nutrition and other areas.

Participant: I agree with that.

That's very important. I'm saying that it's very important, but we can do a better job ourselves. Why get Medicare into this? I'd rather see Medicare concentrate on the doctors, the hospitals and increasing the medical problems and doing more for prevention, prevention tests and stuff like that.

The moderator's guide specifically asked participants about the need for information on preventive practices related to hearing and hearing loss. A few participants indicated that they think beneficiaries need more information about hearing. However, this topic did not draw much discussion, suggesting that participants did not have strong opinions in this area.

**A few think there should be more information about hearing and hearing loss, but opinions were not strong**

I think there ought to be more information on hearing though. I think there's a flood of information on everything else, but I don't see as much on hearing as I would like to.

There are a few good, wonderful organizations, but in the general literature that comes out, there's not enough about hearing.

## **OTHER INFORMATION NEEDS**

When asked about other information needs, participants with hearing loss mentioned a variety of information needs related to hearing loss. Several participants said it would be useful to get information about the kinds of assistive devices available and guidance in selecting appropriate devices for their specific needs. Participants thought that the Medicare program might help in this area. *Information partnerships with hearing-related organizations would be particularly effective in providing information to help beneficiaries get good care for their hearing loss.*

### **Hearing-related needs**

#### **Hearing Evaluation:**

They could go to the local [hearing loss organization]... we go around to some of the homes and the places... where we pretty well know there's bound to be a lot of individuals that need help with hearing aids... And we try to talk to them. And they're so grateful... For instance, we would steer them to a particular hearing aid specialist that we know gives them a test, and varies his test. And then they come back another day and he tries out three or four different hearing aids and runs the test again to find out which particular type hearing aid is helping the person, not 'this is the one I sell...' But that's the way to do it... You go there. You spend the day in tests. And you come back another day and they will test you the same way as they did the first day, using the different hearing aids. And they determine which one is the best for you. And then they tell you to go somewhere and you can buy it at a reduced cost... The average person don't know this, but this is the kind of help that they need badly. I don't know if Medicare can do anything here, but there's a huge, wide open area here, because they don't do anything. They don't pay for tests. They don't pay for equipment, nothing.

#### **Assistive Devices:**

I think the biggest help, what would help me, like I'm trying to decide do I want the digital hearing aides. I think that's where the government—some agency should evaluate. There are so many different kinds of hearing aides. I'm not competent to judge.

Especially now, you're having trouble because they are making so many advances on these hearing aids, that every year it's new.

Moderator: Right. Do you find there is enough information about the hearing assisted devices?

Participant: I think it's almost zero.

Participant: That is a serious problem in our community I think.

#### **Evaluating Providers:**

I wish there was something Medicare could do as far as the hearing aid dispensers.... [A] way of evaluating them like we do the doctors and the hospitals, I think it would be a whole lot easier for most of us.

Participants with hearing loss noted that the Medicare program is not an obvious source of information about treatment for hearing loss because there are many hearing-related needs that are not covered by the program. *It will be important to identify effective information partnerships if HCFA chooses to provide information about care for hearing loss.*

### **Medicare is not an obvious source of information on hearing loss**

Participant: There's so much to be done in this area... And with the average person that has a hearing problem in particular, it's no information from Medicare, because the first thing that they're going to hear, 'oh Medicare doesn't cover that.' So therefore, the individual is turned off. And it's true. Medicare doesn't cover the test, the hearing aides and all that. So these individuals don't know where to turn.

Moderator: Are you saying—what you're saying is that if, when Medicare doesn't cover something, they don't give any information about it? Is that what—is that the gist of what you're saying?



### **The Medicare program might help with some hearing-related information needs**

Participant: Why should he follow up if they don't cover it. Why bother following up. So they go to some friends or some organization... and try to get some information, if they know about it. If they're in the dark, they'll just go on their... but that's not the way to go. They're not really going through the proper professional steps. And I think Medicare can do something to improve in this whole area of helping people with hearing loss, because they're starting from nothing. So they're bound to improve as they go along. And even some guidelines if they won't cover [the care].

Moderator: So what we're saying is that people need information about what to do if they think they have a hearing loss, and where to go. And you don't really feel that there's enough information at the moment out there for these people...

Participants with hearing loss also had general suggestions for the ways they would like to see information presented. *Participants want simple information that is concrete and that is presented from the beneficiary's perspective.*

### **Simple information**

Instead of writing books like this, which I equate similar to... your taxes, and somebody gives you publication 760, or whatever it is. Sure, if you read it enough and go back and forth, you'll be able to do something, but you won't be sure... And that's what you have here. Maybe not as involved, but along that line. You need something short and sweet that if Medicare could tell you... And if they come out with another book like this, it would be a disaster in that form. You need specific questions from the point of view of us... What do we need to find out? What are we going to be faced with? And how do we go about this, starting with the doctor, or your insurance company, or wherever it is that's important. They could do that. And it would be so helpful to us. And in the end they will have less questions, less problems and less expense to run the program if we knew better what we were doing and how to do it.

### **Information presented from the beneficiary's perspective**

I often wish the senior citizen groups would have someone to go in to speak to them, the experienced person, not just a sales pitch, but a person... like all of you, would be very representative to go into a group of senior citizens. You have experience. You have problems. We all have messed with that. And I think that that's the kind of speaker senior citizen groups should have. I think that would be a great benefit.

## **3.4 MAJOR FINDINGS FOR BENEFICIARIES WITH VISION LOSS**

The moderator's guide for focus groups with beneficiaries who had vision loss differed from the general moderator's guide used with most other beneficiary subgroups. For beneficiaries with vision loss, we were particularly interested in their preferred information sources and their reactions to alternative media. Therefore, focus group participants with vision loss spent less time talking about topics directly related to their information needs compared with other beneficiary subgroups, and

relatively more time talking about topics directly related to preferred information sources and alternative communication media.

Participants with vision loss showed less variation than other subgroups in terms of their information-seeking preferences. Among the participants with vision loss, there was a general preference to seek focused information when it is needed to address specific questions. Participants mentioned that they value trained sources who understand beneficiaries' questions and answer them consistently. These participants did not want to work through extraneous information in order to get the specific information they need. A small number of participants said they were interested in receiving general information about the Medicare program and what it covers. There was also a small number of participants who indicated that they don't need additional information about Medicare because the system works smoothly for them. None of the participants drew links between their information-seeking preferences and their vision loss. Therefore, it is difficult to determine whether the relatively high portion of reactive information seekers among these participants is related to their vision loss.

<b>Most prefer specific information when they need it</b>
If I have a question, I just get on the phone and call Medicare and ask them.
Send me something that is interesting. Don't send me something that is not concerned for me, but something that they know I know because I go to a doctor and they see my bills. Send information about those things.
Moderator: Is there information that you don't get but that you need?
Participant: I think one only finds that out if that particular needs comes up. Then it's like insurance. Do I have this covered or not covered?... Until that need comes up for that particular person... other than when we'll go back to the brochure...
Moderator: I think you need to make a phone call or two or three.
Participant: I want to make one phone call. I'm not making two or three.
<b>Small number want to receive general information about Medicare and what it covers</b>
I just think there should be more information about it. I don't think there is a lot of information and I think some people understand easily and others don't.
Now, I think they should make more information available, because, like I said, my mother... was on Medicare and everything. And we had no idea that these things were available.
Because, as I said, before I was even aware of the benefits that were available, I was automatically channeled in... Because I was on a disability program for 24 consecutive months in October, at the end of the 24 consecutive months I was sent my social security—my Medicare card, without any explanation.

**A few don't need information about Medicare: The system works smoothly without their involvement**

They sent a booklet out some time ago. I received that. But I haven't had any reason to get information.

I've never had any problems except what they say is correct. They send me a form in detail, like that. I accept that form. I have supplementary insurance to take care of what Medicare does not pay.

I don't know of any organization that I could pick up, 1-800 and you are HCFA, or whatever it is... I never thought to do that.

I've never had any problems with it. Any time the doctor presented a bill, they always took care of it so I have no complaints.

### **BASIC PROGRAM INFORMATION**

A few participants with vision loss had very general questions about the Medicare program. These questions suggested that they could use basic information about the program. The basic questions raised were similar to questions asked by beneficiaries from the general population. Some participants had more specific questions about the Medicare program. Their specific questions indicated that these participants understood the basic program structure and were more focused on details that would help them use the program effectively. Again, these specific questions were similar to questions asked by beneficiaries from the general population.

**Some basic questions about Medicare**

I have a question... I became eligible for Medicare before I became 65, because of a disability... However, I didn't know that there was a—is there a choice? Do you join, or do you just become? Do you join under your own volition?

I'm confused about... But if you go with an HMO, are you still on Medicare?

**Some specific questions about program details**

I have a question for you. Every year the Medicare deductible is usually raised. What is it this year?... The only way you're going to find it out is—do you people know what the Medicare deductible is this year?... The only what we're going to find out is to read it in the newspaper, and we don't read newspapers. So we don't know. The only other way we're going to find out is when our check is deposited...

The codes mean a lot. If you put the wrong code down, you can get less or nothing. The code is very important.

Information about their costs under the Medicare program was important to these participants and they reported diverse experiences accessing information about their Medicare costs. *The diverse experiences may be related to vision loss if most information is available through print media. In general, beneficiaries with vision loss would benefit from regular and standardized information about their Medicare costs. Medicare could influence beneficiary satisfaction by providing clear, standardized information about personal costs under the program on a regular basis. For beneficiaries with vision loss, it will be important to provide information through a variety of media.*

#### **Mixed opinions about availability of information on Medicare costs**

Participant: I don't get a notice from Medicare.

Participant: The only notice I get is when they raise it.

Participant: Well, like she says, she might throw it away.

Moderator: But what kind of notices do you get?

Participant: The only notice I get is when they raise the fee.

Moderator: That's what we're talking about.

Participant: I don't get a notice that—what the fee is.

Participant: We get one every year.

Participant: I don't.

Yeah, I get a yearly statement that you get as to what you got and what was taken out. I think on that same statement they tell you what the thing's going to be next year.

I have to wait for my statement to come in the end of the month from the bank to find out the difference that was taken out of the check before it was deposited to know if it went up or not.

Some participants with vision loss thought it would be helpful to receive information about available information resources and telephone numbers, but many participants said they know who to contact when they have questions about how to get answers when they have questions about Medicare and their coverage. *The toll-free telephone numbers on their EOMB forms and social security offices are particularly valuable points of contact.*

#### **Some wanted information about resources and contacts**

I didn't know anything about how to get any help either. And a friend of mind, ...she happened to have the phone number of the line, association help. Otherwise, I never would have known about it.

#### **Most knew who to contact**

Moderator: And how did you know to call them?

Participant: Well, I think it's on the form. I think it's on your explanation of medical benefits form.

Participant: And I think by calling even social security there would be somebody there to answer questions you have in mind, about social security, especially if you're on Medicare yet. Whether they take it or not...

Participant: There is a 1-800 number... Maybe it came when they sent that information that they send...

Participant: I think it's on the statement.

Participant: You can also get it from social security....

Although participants with vision loss knew who to contact to get answers to questions about their coverage, they also had a variety of questions about their coverage under Medicare. Some of these questions were general, suggesting that at least some of these participants were unfamiliar with information covered in the Medicare Handbook. This may be related to their vision loss and difficulty accessing information provided through print media.

*For beneficiaries with vision loss, it will be important to identify ways to either substitute or supplement printed Handbook information with information provided through other media. An important strength of the Medicare Handbook is that beneficiaries receive it passively, without asking for it. It will be important to provide supporting or supplementary information that has the same passive feature. It is important to note that beneficiaries with vision loss are not the only subgroup likely to benefit from receiving supplementary information through a variety of media. Other subgroups likely to benefit include beneficiaries who are dually eligible for Medicare and Medicaid, Hispanic beneficiaries, beneficiaries with low educational attainment and individuals about to enroll in Medicare.*

Questions about Medicare coverage
Excuse me. One of the gentlemen referred to—do you have a booklet that explains what Medicare will and will not provide?
Participant: I'd had a mammogram and I was told that they would only pay every other year.
Moderator: Who told you that?
Participant: My doctor's office. But he ordered it for every year. And I tried to find out, and so I went ahead and had the mammogram and submitted it and they did pay because it's a check-up that I have to have every year.
There's another area I'd like to ask about. If they name, like, you know, the home health care that Medicare covers if your doctor approves it. I have friends who live alone, they're widows and widowers, and cannot often see to cook or to clean yet they want to stay in their own home. Uh, is there any type of that Medicare could cover, help, you know, that would make them more independent.

Like the general population beneficiaries, participants with vision loss were very interested in receiving frequent information about changes to the Medicare program. *This is another area where HCFA can have a large impact on beneficiary satisfaction. It will be important to provide information through a variety of media so it is accessible to beneficiaries with vision loss. Again, it is likely that this information, provided through diverse media, will be useful to a variety of beneficiary subgroups.*

**More information and more frequent updates about program changes**

Medicare changes every year. Nobody knows what the changes are. If the government can send income tax books in the mail to every family, to every individual, why can't they send out, on a yearly basis, a new Medicare report as to what the changes in it are? Even if they have large print that they can send out to the ones that are visually handicapped, or a regular print that at least we can give it to some member of the family to read to us. As it stands now, no household has a current Medicare pamphlet.

I think—we don't hear if it changes either.

Participant: What more Medicare information do you want?

Participant: Changes in the Medicare laws.

Moderator: Is that something you think you should get? Updates? Updates of what?

Participant: Of the book.

Participant: Of all the different changes because they do change things.

Moderator: Does everybody agree with that about the updates?

Participant: Once a year.

Participants with vision loss also had specific questions about Medicare coverage for vision-related needs. Since these needs are specific, it is best to address them through information interventions that are developed specifically for beneficiaries with vision loss. *Partnerships with organizations concerned with vision loss are likely to be useful mechanisms for providing specific information about coverage for health services related to vision loss.*

**Participants want information about coverage for vision-related needs**

I'm legally blind. And I'd like to know if I'm eligible for devices.

I would like to know for sure what Medicare would cover when it comes to aids for helping you see better.

Do you mean if we would have just called Medicare they would have told us the things that were available for a legally blind person?

And she bought me several things, very, very expensive.... So if indeed Medicare could gather all of these materials and kind of set some price limits on what they are willing to pay and what the traffic will allow, well, then, I think that would benefit us all.

Participant: Oh, I had laser surgery, I don't know how many times. And I had to get new glasses, and they said you pay.

Participant: Because it kept changing.

Participant: I don't know where they get these dividing lines.

There is a closed circuit TV. Well, it's not a closed circuit TV but that is what they call it. It's a magnifying unit that you can put underneath and adjust it and that is the one that will help me. It's the only thing that will help and I wanted to know if they do cover it. I do have supplemental. If they don't pay for it then I have supplemental to see if they will do that.

Participants with vision loss were similar to general population beneficiaries in wanting information about the Medicare program that is easy to find and easy to understand. *It will be important to develop information interventions that use language that is familiar to beneficiaries. In addition, HCFA should use information from quality control and quality assurance programs proactively to address general beneficiary concerns about accessibility and reliability. Audio cassettes are one effective method for addressing difficulties with access to information due to vision loss.*

**Participants want simplified information that is accessible and reliable**

Moderator: How would you like to get that information?

Participant: Very easily!

Are they easy to decipher? Sometimes they're so difficult, sometimes these books are so hard to understand what they're saying. I mean, are they in a simple form...?

Oh, I'm not particular where it comes from, as long as it's accurate and I know how to access it.

Participant: I would like, if you called somebody and they answer the phone, if you can get the same information, like from Medicare, if two different people answer the phone, do you get different exchanges?

Participant: That's exactly right.

Participant: Sometimes you do! So, I don't know, I would like it to be consistent.

**Participants also want information that is accessible to beneficiaries with vision loss**

If they want to give us any information, they should do it in a form that we can use, which is like we were discussing, an audio cassette form, something of that nature. Something that's easy for us. Or, if someone has some vision, large type, bold print that can be read.

Now, it's very possible that something has come in the mail, but if it has come in the mail and I cannot see it, I may have either discarded it or lost it. But I would definitely need some kind of oral kind of information fed to me, rather than written information. That's of no use to me at all.

Moderator: But if a person is visually impaired, can you read this book?

Participant: Then we have to get somebody else to read it for us.

Moderator: Or perhaps, get it on cassette.

Participant: That's right. That would be good.

Participants with vision loss were very aware of limits in Medicare coverage for equipment to help beneficiaries deal with vision loss. As a result, beneficiaries with vision loss feel particularly vulnerable in making decisions about purchasing equipment for themselves. *Several participants said they would value information from HCFA to help them make difficult decisions about purchasing equipment to help them deal with vision loss. Partnerships with organizations working on vision loss would be an effective method for addressing this salient information need.*

**Participants had concerns about uncovered needs related to vision loss**

How about changing the rules and bending the rules and giving us a break on glasses and some of the adaptations that we need. This is what I really feel we need.

I really feel that Medicare should help defray the expense of the visual aids that we need, definitely.

I live alone. And I've always been very independent. And I really could not—I couldn't write my checks, I couldn't read my mail. I couldn't function without them. And I really don't use them to read books, because it's too tiring.... Just for daily living,

Participant: And she bought me several things, very, very expensive... The little hand held magnifying glass that's lighted, it requires batteries and bulbs...

Participant: Medicare doesn't pay for any of that.

Participant: Nothing at all?

Participant: No.

Participant: They will pay for your low vision examination.

This is one thing I feel Medicare should do: at least partially pay for these visual aids, because without them, we can hardly function.

There are a lot of things we need that we don't get help for. I think we should get some help on this.

**HCFA could serve as a clearinghouse for vision-related information**

Well, if something new comes up to help us, which they are working on all the time... If something new comes up, just drop us some information about it or bring it out some way where we would know about it and not have to just wait. There is a lot of information. My daughter got a letter someone gave her a while ago to read of a place you could go and buy these glasses. When I showed it to my doctor, he shook his head and said, it is a scam. So, where is the safe place to go and listen to?

I think this advertising on TV of equipment of all kinds that they advertise. Most says, Medicare will pay for it. They are pushing products that's costing Medicare an awful lot of money that's not needed.

And she bought me several things, very, very expensive.... So if indeed Medicare could gather all of these materials and kind of set some price limits on what they are willing to pay and what the traffic will allow, well, then, I think that would benefit us all.

## CHOOSING A PROVIDER

Only one of the four vision-loss focus groups spent time discussing the information they need to choose health care providers. Like general population beneficiaries, these participants with vision loss preferred relying on personal contacts and recommendations when choosing a primary care provider. They mentioned a few other resources, including hospital referral resources, lists maintained by the American Medical Association and directories provided by insurance providers. However, most participants preferred speaking with people they know to find a primary care provider.



In general, participants with vision loss reported relying on their primary care providers for referrals to other specialists. Again, this result is similar to findings from focus groups with participants from the general beneficiary population. Vision care specialists were different. In the case of vision care specialists, participants reported that they prefer to rely on people they know to make recommendations. None of the participants with vision loss reported wanting to receive information from HCFA to help them select a health care provider.

<b>Reliance on recommendations from friends and family</b>
Also, then, ask people in your community if you've heard about so and so and are you happy with him.. Do they have other physicians?
I believe by word of mouth is about the best...
Participant: Doctors have their own referral system.
Participant: There's nothing wrong with that...
Moderator: So you trust that information?
Participant: I wouldn't use that information. I would go the other route, neighbors or whatever.
Moderator: So you kind of really trust the word of mouth.
<b>Primary care providers identify specialists</b>
When you choose your primary care, I think that's one of the most important steps in your life. And if you choose that guy, then you can rely on them to refer you to the needed specialists.
<b>Personal contacts and recommendations from friends for selecting vision care specialists</b>
Moderator: And how did you find a retina specialist?
Participant: Well, two ways. A friend of mine, because his wife had a problem... and he gave me the name. In the meantime, I also looked in the directory to see how many, if any, were listed. So between the directory and the friend of mine, I went to the one that the friend recommended.
I went to one my mother was going to.
My eye doctor sent me to a specialist... and after I didn't like him, then I went to the eye doctor that did my husband's cataracts.

## MEDICARE HMOS

The moderator's guide for focus groups with beneficiaries with vision loss did not include discussion of Medicare HMOs, and the topic did not generate any spontaneous discussion in these groups.

## SUPPLEMENTAL INSURANCE

Many of the participants with vision loss received supplemental insurance through their former employers. Participants reported that their former employers were a particularly valuable source of information about their supplemental insurance options.

### **Employers are an important source about supplemental insurance**

Their supervisor, the boss down there told me I would be a lot better staying with the plan I have. He said, because if you go on your own, it's going to cost you twice as much. So that's the plan I'm paying today.

I belong to a retired group of employees. And every year they go to the different insurance companies and supposedly pick the one they feel is going to be best for the group... At present we have 3 different units... You can choose which one of those units you want... but that's how I know about insurance.

I retired... [and] they suggested a supplemental insurance at retirement. That was merely a suggestion... So that's how I found out about my insurance. And I've just been with them since I retired. If I had any questions, I would call them.

### **Friends and supplemental insurance companies are also useful sources for supplemental insurance.**

#### **Friends:**

Well, I depend on a very good friend of mine..... I just dial a few people that I know personally and I ask.

#### **Supplemental Insurance Companies:**

It's all broken down to where they'll give you the brochures, if you send for it, where you make a comparison check and the prices that you would have to pay.

My supplemental insurance that I have to take care of the charges that Medicare does not pay, they put out a complete list of what they cover and what Medicare covers.

Moderator: Do you all feel that you had enough information about your supplementary plans to make a good choice.

Participant: Yes.

Participant: Well, they mail you things.

I've found [the insurance company] to be very nice when I call for information and tell them what I have and need. They've been very helpful.

I had a representative come to the house. That was personal contact and if I needed an answer someone was there. If I try and read something it wears me out, the strain of trying to read.

A few participants noted that supplemental insurance was a complicated and difficult choice. One participant reported that, initially, she selected her supplemental plan somewhat arbitrarily with the idea that she would do more careful research and change her coverage when she'd had enough time to gather the information she needed.

#### **Supplemental insurance is a complicated choice**

But there is a problem... because again, there are so many different plans, that you've got to be behind closed doors to try to get right information.

Yes. And without knowing what my Medicare benefits were, I simply... bought into Blue Cross/Blue Shield. And I'm not even completely aware of what I have with them right now. What I was planning to do was to be covered in the meantime, so that I would give myself a few months to investigate the possibilities of what these other things were, and what was available. And then I have the option, I think some time this year, toward the end of the year, if I'm not satisfied or if I want something different, I could change to a different form of supplemental insurance.

## **STAYING HEALTHY**

Participants with vision loss identified a variety of sources for information on ways to stay healthy.

#### **Health care providers are an important source on ways to stay healthy**

Moderator: Do you get the information that you need to stay healthy?

Participant: Well, I got mine from my physician, ophthalmologist.

I go to my eye doctor every three months and to my internal medicine doctor every three months regular and they keep me updated on my health condition and everything. My biggest problem is my eyes.

#### **Participants also mentioned mass media as useful sources of preventive information**

Usually it's on television. You know, every other week they've got something new.

The newspaper has pretty good articles in it.

I went to a gynecologist for years. He never told me to get a mammogram. And when Nancy Reagan got it, and I said, I better go get one, and I had cancer. And I was seeing a gynecologist every year. He didn't tell me.

Moderator: Where do you get your information?

Participant: Mostly the media. Not the print media, but the electronic media.

Participant: I think basically there's a lot of information on television, radio, the media. It has a lot of information on the latest health news

Moderator: Do you trust what you hear?

Participant: Some. Some you don't pay attention to.

#### **A few mentioned community resources for information about staying healthy**

At the senior center they usually have a dietician come in and she talks to us as far as foods are concerned and what you can eat and what you shouldn't eat.

Participants with vision loss agreed that they would like more information about preventive vision care.

<b>More information about protecting vision</b>
Moderator: Do you feel that you get the information you need about vision testing, glasses or contacts, or other ways of protecting your vision? Do you feel like you get enough information about that? Participant: I don't think there's enough information to the public about it.... Participant: You have to dig for it.... Participant: There hasn't been that much interest in it.

### **OTHER INFORMATION**

No participants with vision loss mentioned any additional needs for other types of information.

## 4. SOURCES OF INFORMATION

This section describes beneficiaries' comments about and attitudes toward potential sources of information about Medicare. Our analyses draw on two parts of the focus group protocol: (1) participants' descriptions of actual information-seeking experiences and (2) results from card-sorting exercises that participants used to rank alternative sources of information according to the amount of information they had received from the source and how much they trusted the source to give them accurate, complete information about Medicare. The general population focus group report describes the card sort exercises in more detail. The card sorts were used with the low education and hard-of-hearing groups, but not with the low vision groups.

The focus group participants are not a statistically representative sample of either the Medicare population as a whole or of the subpopulations of interest, so any quantitative analysis of the results cannot be generalized. Quantitative rankings do provide a summary of focus group participants' attitudes toward the eight information sources ranked. Exhibit 4-1 shows the mean, median, and modal rankings for the eight sources, separately, for the amount of information received and for trust. Exhibit 4-1 presents results for the general population, for the low education groups, and for the hard-of-hearing groups. In all cases, lower numbers reflect better rankings. For example, the source assigned a ranking of 1 for amount of information was first in terms of amount of information, and the source assigned a ranking of 1 for trust was first in trustworthiness. Likewise, a source assigned a ranking of 8 for amount of information was last in terms of amount of information, and a source assigned a ranking of 8 for trust was last in trustworthiness. For the hard-of-hearing groups, 10 sources were presented, so the median and mode rankings are based on 10. The actual mean rankings have been adjusted (multiplied by .8) so that they may be compared directly with the means for other subgroups.

We will discuss results from Exhibit 4-1 in the following sections, focusing on a single beneficiary subpopulation at a time, and covering reactions to each source in turn. In this introductory section, we will describe some of the criteria participants said they used to make these rankings. We will also describe group differences.

In the general population report, we identified the following four criteria that seemed important to participants as they ranked information sources:

- Knowledge about Medicare—both the amount and accuracy of information;
- Timeliness of information—up-to-date information available when it is needed;
- Clarity of information—making a complex program simple; and
- Strength and length of beneficiary's relationship with the source.

### Exhibit 4-1

#### Mean, Median, and Mode Rankings for Amount of Information Received About Medicare and Trust of Sources Based on Focus Group Card-Sort Exercises, for the General Population and Subpopulation Participants

Amount of Information	General Population			Low Education			Hard-of-hearing		
	Mean	Median	Mode	Mean	Median	Mode	Mean	Median	Mode
Family and friends	4.42	5	1	4.21	4	1	4.90	6	10
Medicare contractors	3.55	3	2	3.45	3	2	3.37	4	2
Doctors, nurses, clinics	4.10	4	3	3.69	3	3	3.78	4	1
Radio, TV, newspapers	5.22	5	8	4.9	5	3	4.90	7	7
HCFA	4.98	5	7	4.31	5	5	4.38	5	3,8
Supplemental insurance	3.92	4	3	5.21	6	8	3.86	5	7
People in the community	5.69	6	8	5.41	6	7	5.48	7	6,7,9
AARP and other groups	3.60	4	1	4.72	5	1	3.03	4	1,3,5
Hearing health care specialists							4.98	6	4,9
Hearing-related organizations							4.57	5	5

Trust of Sources	General Population			Low Education			Hard-of-hearing		
	Mean	Median	Mode	Mean	Median	Mode	Mean	Median	Mode
Family and friends	4.97	6	8	3.07	2	1	5.06	7	4,10
Medicare contractors	3.71	3	1,2	3.36	4	4	4.28	5	3,5,8,9
Doctors, nurses, clinics	3.79	3	3	5.07	5	7	3.05	3	1
Radio, TV, newspapers	6.32	6	8	6.57	6	8	5.68	7	5,8
HCFA	4.09	4	1	2.47	2	1	3.20	3	1
Supplemental insurance	3.50	3	2	4.21	4	3	3.68	4	4
People in the community	5.62	6	7	5.71	6	6	5.64	7	9
AARP and other groups	3.65	3	1	4.53	5	6	3.54	4	3
Hearing health care specialists							4.71	5	2,5,9
Hearing-related organizations							4.48	6	7

These criteria seem to hold up as important for most of the beneficiary subgroups covered by this report. There was, however, one difference across the subpopulations. Among both hard-of-hearing beneficiaries and those with vision loss, an important criterion described by some participants is whether the source provides assistive devices for hearing or viewing information.

One set of statistics we use to make some general observations about how the rankings compared across the beneficiary subpopulations is the range of the mean and median rankings. The range is a measure of dispersion that represents the difference between the highest and lowest ranking. For the general population groups, the range of mean rankings for amount of information was 5.69 (“lowest”)

minus 3.55 (“highest”), or 2.14. Similarly, the median range was 6 minus 3, or 3. For the trust rankings, the mean range was 2.82, and the median range was again 3. The wider the range between highest and lowest scores, the more uniform the rankings were across participants within a subgroup. The widest possible range is 7, which would mean unanimity on the highest and lowest scores. The narrowest possible range is 0, which would mean no agreement at all on the rankings. The ranges are important in interpreting the results; larger ranges imply more agreement across participants within a beneficiary subgroup and hence more strength of opinion or uniformity across participants from a specific beneficiary subpopulation.

The mean and median ranges for low education (1.96 mean range, 3 median range) and for hard-of-hearing (2.45 mean range, 4 median range with 10 categories) were very comparable to those of the general population groups. The hard-of-hearing groups were also similar to the general population groups in range of rankings on trust (2.63 mean range, 4 median range). The low education group, however, had wider ranges for trust (4.10 mean range, 4 median range), indicating more agreement within and across the low education groups on this factor. In general, the mean ranges for trust were larger than those for amount of information. This tendency was especially strong for the low education beneficiaries.

Comparisons between the rankings for amount of information and for trust within beneficiary subgroups provides additional insight. Many beneficiaries gave identical rankings for trust and for amount of information. To the extent that the rankings are different, they suggest gaps between where information is coming from and where it should be coming from (from the beneficiary’s perspective).

The gap comparison shows that both low education and hard-of-hearing groups appear to be receptive to receiving more information from HCFA, with gaps of 1.18 and 1.84, respectively. The very large gap between amount of information and trust for the low education beneficiaries, combined with the large range in rankings, indicates that “brand recognition,” i.e., knowing that information about Medicare is coming from the government agency responsible for the program, is particularly important for this subgroup. Alone among the subgroups studied to date, the low education beneficiaries also show a gap between trust in and amount of information received from family and friends, indicating they would like more information from this source. The gap for mass media suggests that low education beneficiaries, like several other subgroups, would like less information from that source.

## **4.1 MAJOR FINDINGS FOR GENERAL POPULATION BENEFICIARIES**

### **FAMILY AND FRIENDS**

In the general population, the rankings for “family and friends” were bimodal. Participants ranked family and friends either very high or very low. Few participants were neutral about family and friends as sources of information. Participants who had older spouses, older friends and family members, or friends and family members in medical professions reported that they used their friends and family as frequent sources and that they trusted the information. People who reported relying on family and friends as frequent sources of information were more likely to be reactive rather than proactive about seeking information, and they also seemed intimidated by information from “official” sources. People who said they do not get Medicare information from family and friends generally agreed that their family and friends mean well, but they do not have the required experience with or knowledge of the Medicare program. Family and friends were most often cited in discussions as sources of information about supplemental insurance and choosing a doctor, as well as for general information about Medicare.

### **INSURANCE COMPANIES THAT PAY CLAIMS FOR MEDICARE**

Among participants from the general beneficiary population, there was considerable confusion about the difference between Medicare contractors, HCFA, and supplemental insurance companies. Many participants did not make clear distinctions as they ranked the information sources. Participants ranked Medicare contractors high for the amount of information provided but low for trustworthiness. We observed a range of reactions to Medicare contractors as information resources, probably in part because beneficiaries’ experiences with contractors differed across the focus group sites. General population participants who said they do not trust their Medicare contractors as sources of accurate information cited delays, mistakes, lack of follow-through and general distrust as reasons.

### **DOCTORS, NURSES, OR CLINICS**

General population participants reported that they rely on and trust information from doctors who are willing to take the time to talk with them. Participants’ relationships with their providers were related to the likelihood they would rely on information from their doctors. Participants who had good



relationships with their doctors trusted the information they got from them; participants who had weaker relationships with their providers were less trusting of information they got from their providers and said they relied more heavily on other sources. Participants also reported relying on providers as information sources because of their specialized knowledge and expertise.

## **RADIO, TELEVISION, AND NEWSPAPERS**

General population participants ranked the mass media low both in amount of information about Medicare and in trust. In discussing their distrust of mass media, participants mentioned perceived sensationalism in media coverage, shallow treatment of news stories, and bias that some participants associated with commercially-provided information. Several participants mentioned political “scare tactics” used by the media, particularly in reporting about Medicare. (Most of the general population focus groups were held during the 1996 Presidential campaign or shortly after the election.) Some general population participants felt differently, however. While acknowledging the shortcomings of radio and television, they said that discriminating viewers and listeners can pick up useful information, perhaps identifying topics of interest that can be pursued through other channels. Some participants also identified particular radio and television programs that they felt were useful and that they trusted.

## **THE HEALTH CARE FINANCING ADMINISTRATION**

Besides being listed as a source of information for the card-sort exercises, HCFA was also discussed at the beginning of the focus group sessions, under the topic of “Who is Medicare?” Except for former Federal employees, virtually no one in the general population groups supplied HCFA’s name as the agency responsible for Medicare, and only one or two participants per group recognized the name once the moderator said it. With these discussions as background, when the groups got to the card sort exercises, they were generally able to identify the HCFA card properly, although in a few cases there was still some confusion. General population participants ranked HCFA low in terms of the amount of Medicare information received, but high in terms of trust. A few participants described negative experiences with or attitudes towards HCFA. However, a larger portion of participants said they trust information from HCFA because HCFA is the agency responsible for the Medicare program. *While few participants said so directly, the underlying inference is that general population participants would be receptive to more information that explicitly identified the Medicare program as the source.*

## **SUPPLEMENTAL INSURANCE COMPANIES**

Some general population participants were not clear on the distinctions between Medicare contractors and supplemental insurance companies. However, virtually all of these participants had some kind of supplemental coverage and were able to identify it during the discussions. General population participants ranked their supplemental insurance companies high both in amount of information provided and in trust. They ranked their supplemental insurance companies highly because they are responsive to requests for information, they answer beneficiaries' questions, and their answers are generally comprehensible.

## **COMMUNITY RESOURCES**

The Inventory Reports identified community resources as particularly important for beneficiaries with special communication needs. Our focus group results suggest that community groups are not particularly important resources for the general beneficiary population. General population participants ranked community sources low both in amount of information about Medicare and in trust. Most participants seemed to have little experience with these sources, or at least didn't think of them as sources of information about Medicare. With further prompting, participants were able to identify community resources they might use for information.

## **ORGANIZATIONS SUCH AS AARP AND MAGAZINES FOR SENIOR CITIZENS**

Many general population focus group participants belonged to AARP, and most of these members were very positive about AARP as a source of information. Although this category of sources was intended to include other advocacy groups, virtually all discussion in this category was devoted to AARP. Participants ranked senior organizations high in amount of information and in trust. Participants said they ranked these organizations highly because the organizations are effective in looking out for the interests of senior citizens. Participants said that AARP's materials are easy to understand and very relevant to their needs. Many beneficiaries who belong to AARP joined well before they became eligible for Medicare, so they are used to receiving information from this resource. In a few general population groups, participants mentioned losing trust in AARP because of perceived commercial and/or political interests.

## **OTHER SOURCES**

Several general population participants mentioned other sources of information about Medicare during the course of the focus group discussions. Former employers were mentioned by a couple of participants, and other sources mentioned included lawyers and the National Association of Retired Federal Employees (NARFE). In discussions about information on ways to stay healthy, health clubs and nutritionists were also mentioned as sources of information.

## **4.2 MAJOR FINDINGS FOR BENEFICIARIES WITH LOW EDUCATIONAL ATTAINMENT**

### **FAMILY AND FRIENDS**

According to card sorting results, beneficiaries with relatively low education had much the same view of family and friends as beneficiaries from the general population. The following quotations illustrate several reasons mentioned for counting on and trusting information from family and friends, and, conversely, for not doing so.

### **Beneficiaries with low education on family and friends**

#### **Some rely on and trust information supplied by this source**

Well, they are close to me and my family. Maybe I'll ask them since my mind has gotten sort of bad. Where must I go to see about this such and such a thing or social security. They will tell me. And, I go there and ask them, or a friend, whichever, and I have some close friends too. We work it out.

I don't particularly go to them or anything. I just happen to have relatives that have reached that age where they get those benefits. Without even asking it filters through. Then when I got to that age, they gave me the information. They would ask me how I was and so forth.

I've got my family that really know about it and I trust them.

Well, I said family and friends again, because I feel like you can trust your family. I can't say if you have real good friends you can't trust friends, but a lot of our friends are not friends, they're just acquaintances. We have very few friends. But I feel like your family, you should be able to trust. And if we can't go that way, you just have to kind of study and work and put your hands in the hands of the Lord and do the best we can do.

Seemed like they get all the information. Because you know, when you start talking you get a lot of information from your friends and family too. Of course, I don't have much family any more, but—they're all gone.

I have a—because I have a niece that has worked in a doctor's office all of her life and handled the insurance end, I feel like she knows it from A to Z.

#### **Others are more wary of information from family and friends**

Though you trust family and friends, how much do they really know about Medicare? They wouldn't mislead you, but how much do they really know?

I've learned through experience. You can't put too much on what family and friends say. They say what they want you to hear.

Maybe experiences that they've had... if it suits my purpose I would. You know, look for them even more.

You have to be kind of careful, because sometimes information may be good for you. You have to really weigh everything that you hear before you even try it.

The tricky thing about family and friends, and I think we all would agree on this here. We're all old enough to know, that your heart gets in the way when you're getting the information. You know, is it true information, or am I believing this person because I care for them. So it can be misleading for you in particular.

## INSURANCE COMPANIES THAT PAY CLAIMS FOR MEDICARE

Although beneficiaries with lower education rated Medicare contractors highly in the card sort exercises, both for trust and amount of information, the only substantive conversation about Medicare contractors in the four groups was surprisingly negative.

<b>Some low education beneficiaries find Medicare contractors less than helpful</b>
Moderator: Do you think you trust them to give you accurate and complete information?
Participant: Not always. It depends on who you get. Some of them act like they don't know what they're talking about.
Participant: I thought when they answer the phone, they put you through to talk. Some of them you ask them something and they say they'll find out for you, can you hold on a minute. Then they come back and you wonder if they took the right information.
Participant: I think there's some things they don't want you to know. Or either they don't care.

## DOCTORS, NURSES, OR CLINICS

Lower education participants rated medical providers highly for amount of information received, but very low on trust. Alone of all the subgroups studied thus far, low education beneficiaries had a substantial negative gap between amount of information and trust for medical providers. For some beneficiaries, the lack of trust related to medical care as well as information about Medicare, but other beneficiaries felt that their medical providers were either not knowledgeable about Medicare or wouldn't take the time to talk with them about it.

**Less-educated beneficiaries are skeptical of Medicare information they may get from medical providers**

In my opinion it was very hard for me to put family and friends last, because it was between doctors and friends. Doctors, as far as I'm concerned, they say lawyers is the lowest on the trust level, but I put doctors because it's debatable. I've got, well, most of the information I've gotten from doctors was wrong. Not very much, but needless to say, I had an operation which I shouldn't have had. My experience with doctors has been negative. Since I had an operation which I wasn't supposed to have, I probably was ruined for life as far as my concept of doctors.

I don't have them clear at the bottom, but the very next. My experience, basically with doctors is, experience with other people. Friends and relatives who have had experiences with doctors. They get prescriptions they shouldn't have. They mismanage the money. They are more interested in the material things than their oath. So, I don't put much trust and faith in doctors. Their information, in other words if they are going to give you information, that information will put money in their pocket more than anything else. That's why I don't trust them that much.

Moderator: Did you have doctors last too?

Participant: Yes, I certainly did. I get most of my information from them, but I don't think it's reliable. I don't question anything, though, I go along with the system and what my vibes, intuition says, that's what I go by.

It's hard for me to really put my trust in doctors, not only for the reasons I previously described, but the mere fact of all the latest surveys, even by the AMA that say doctors are prejudice. Like all these new procedures and things, I wouldn't get them. Even the AMA says that. They are the ones who conducted the survey and they said it.

I had the doctors, nurses and clinics next to the last, but it's my choice where I get the information and how I trust it... There are too many prejudices with the doctors and clinics. Obviously, they have a big stake in what's going to come to them, in their pocket. That's why they are not too high on the list. I'd rather get the information from some other source.

Participant: You're paying for his vacation in the Bahamas and the two payments on his Mercedes.

Moderator: So how can you tell what information you'll trust and what information you won't trust?

Participant: If it's something important, it would have to be written in the American Medical Journal, I always thought. But now you find out that even doctors cheat on grants that are given by the federal government, and they fudge them and say the results are there. Now we find out these doctors lied. So what do you really -- what can you trust?

Moderator: So you don't trust the information from your doctor.

Participant: I don't get any. I don't get any information from them, I'm just crawling around in the dark. Probably he could enlighten me with some of it, if you could sit down and talk to him for long enough.

Participant: Depends, I have different doctors for different things and there's some I wouldn't ask any question of. I mean, not that I don't trust them to take care of me it's just they don't have the time to answer, they rush me out of the office.

Participant: I trust them to take care of me but I don't get any answers.

My doctor will explain things as far as he'll give me that time if I have any questions.

**Some less-educated beneficiaries feel very good about their providers**

My doctor is very helpful to me, you know, as far as Medicare. He explains things to me, I mean as far as Medicare.

Well, [my doctor] because I trust him completely. I just think he's the greatest so I trust him.

## **RADIO, TELEVISION, AND NEWSPAPERS**

Less-educated participants were similar to participants from the general population in their opinions about the mass media. While most participants simply did not trust the mass media generally, some found exceptions.

**Most less-educated beneficiaries don't trust the mass media to report accurately, but there are exceptions**

Participant: But if you want information on operations as such... and you're interested in these textbook things, you want to turn to channel 44, 7:00 at night I think on Tuesdays and Saturdays. TLC, cable. It will open yours and will put you right there. . . .

Moderator: So you get some useful information from television.

Participant: Oh, my goodness, yeah. And like I said, we're all apprehensive about operations. And nobody knows this better than I do, because I've had a few of them. And when you see this and the way they do things today..., it makes you feel so much easier and at ease.

Moderator: What do the rest of you think about radio, TV, other media?

Participant: I would trust Channel 44 but that's it.

Participant: Or C-Span. I trust C-Span. You're hearing it right from the horse's mouth.

Participant: Well, who trusts the media?

Participant: Yes. Anybody does, they're really kidding themselves. Okay.

Participant: They're all sensationalists.

Participant: I agree with that.

## **THE HEALTH CARE FINANCING ADMINISTRATION**

Less-educated beneficiaries ranked HCFA higher in amount of information and trust than did the general population focus group participants. These rankings were based mostly on learning during the focus groups that HCFA was the Federal agency responsible for Medicare, although some participants seemed to have heard of HCFA before the focus groups. Despite the high ratings in the card sort, the subsequent discussions brought out some distrust of and dissatisfaction with government.

**Despite high ratings for HCFA in the card sort, some less-educated participants described a lack of trust in or dissatisfaction with government**

Moderator: Okay, you had Healthcare Financing at the top, E. Did anyone else have Healthcare Financing at the top. Okay, there's more agreement this time. What makes you say you trust them?

Participant: They are the ones putting out the money.

Participant: You have to put trust somewhere I guess.

Participant: They are the government agency. If you can't go to them, then where can a person go.

Yes, if it is a program directly by the governmental agency that handles Medicare, then it would be helpful to hear from them. Not anyone else. I'm sure there's organizations that would check them out. See if they are putting out correct information.

You don't get any brochures. You don't get any bill. You don't get any flyers. You get nothing from them.

In regard to that book, Medicare, if anybody, if anybody should give us pertinent, honest information, it should be Medicare, because Medicare is the one that would gain the most in the long run.

Participant: I had E [last].

Moderator: And why is that?

Participant: I never heard of the organization. Very simple.

Participant: Like you said, it's a bureaucracy. You're not going to get that.

Participant: I know. I know.

Participant: They just want to have enough staff people to warrant their money.

Well, I'll tell you. The way the government's going and everything, you just never know who to trust any more. You get somebody and you think, well, now they're honest and not — and before you know it, they've knocked all their points off, you know.

And the government never dismisses anyone if they can't perform a job. They just put them over in a little corner where they can't do too much harm. How well informed are these people . . .? How well do — how much do they actually know about it?

## **SUPPLEMENTAL INSURANCE COMPANIES**

Less-educated beneficiaries ranked supplemental insurers much lower on amount of information and lower on trust than did participants in the general population groups. The group discussion shed little light on this difference. The differences may be due to including HMOs and Medicaid in the category.



<b>Less-educated beneficiaries were less positive toward supplemental insurers than were most other groups</b>
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Well, my supplementary insurance, they never tell me anything about Medicare or Medicaid. They're worried about their portion. They say Medicare is the primary. And then they pay the rest of it.
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## COMMUNITY RESOURCES

Community resources were ranked lowest on amount of information and next to lowest on trust by less-educated beneficiaries. Few reasons were given for this low ranking.

### ORGANIZATIONS SUCH AS AARP AND MAGAZINES FOR SENIOR CITIZENS

Although many less-educated participants ranked AARP highly, on average it received lower rankings than from the general population or most other subgroups. It may be that fewer beneficiaries in the low education focus groups were members.

<b>Less-educated beneficiaries were more mixed in their opinions about AARP than most other groups</b>
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AARP is wonderful. Like I say, we get the brochure, the paper.
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I had H. I didn't fill mine all out, but I had H on the bottom. The one thing that I get literature from AARP all the time too, and they advertise, you know, you can order your medicines and stuff from them at a discount. And when I went to check with them, they weren't any cheaper. In fact, they were higher on some of them. They were higher on some of their medications. So I was disappointed in that, because they claim that they are for seniors, you know, but they're not in medication.
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## OTHER SOURCES

Other sources of information about Medicare mentioned by less-educated participants included health food stores, local politicians, and a State agency for aging.

## 4.3 MAJOR FINDINGS FOR BENEFICIARIES WITH HEARING LOSS

### FAMILY AND FRIENDS

Overall, beneficiaries with hearing loss ranked family and friends as information sources very similarly to the general population. While family and friends were important sources for some, by and large focus group participants felt that other sources were more knowledgeable.

#### **Some hard-of-hearing beneficiaries rely on family and friends for information**

I started out, when I became eligible, my wife and I, we got the books from Medicare. And we read the books, not very clearly. We really don't — we read them. We thought we understood them, but there were a lot of questions. Calling Medicare and asking them the questions does not solve very much. We get better information and found out what it was all about by talking to other people that have been through the process.

Family and friends on top. The reason being that's where we turn first, because even though it's a big clouded mystery, so you bring it a little bit into focus.

I was going to say, I don't know if I'm an addition to this, but I have just observed my husband doing health insurance.

#### **Others find family and friends not very knowledgeable**

Moderator: Okay. What do you have on the bottom of your list?

Participant: Your family or friends, because nobody in my family knew anything about Medicare at all. And believe me, they could care less.

I don't think they do it, you know, deliberately. They're just misinformed.

### INSURANCE COMPANIES THAT PAY CLAIMS FOR MEDICARE

Participants with hearing loss ranked Medicare contractors about the same as did participants in the general population groups for amount of information, and somewhat lower on trust. The participants said that they relied on Medicare contractors for information about claims, but indicated some difficulties in reaching them. In one group (Florida), participants indicated that contractor performance had improved in recent years after being very bad.

**Hard-of-hearing beneficiaries use Medicare contractors as a source of information on claims, but have some difficulties reaching them**

My second [highest ranking for amount of information] I have insurance company that pay claims for Medicare. And usually my point is to contact on a specific paper relating to a specific claim. I have to do that by TTY and I have trouble with that.

I have the 'B', the insurance company that pay claims. I call them first. I wait a long time before I get them sometimes. But I persevere and do it.

**DOCTORS, NURSES, OR CLINICS**

Medical providers were an important source of Medicare information for focus group beneficiaries with hearing loss. They ranked providers second for amount of information and first for trust. As with participants in other groups, it seemed that whether beneficiaries got Medicare information from providers or not depended more on the provider than on the beneficiary.

**Medical providers are important sources of information about Medicare for beneficiaries with hearing loss**

I asked the secretary in the two offices who handled the submission of claims to go by the information. I gave them all the medical details about the accident and the hospitals emergency room and asked them to pursue it. And they did the pursuing and told me that I would get the one, the root canal, that I would not get the other.

I think doctors and nurses, because I found that often they have to provide the specific medical information to go along with the claims. And I could not possibly do that.

Also in visiting doctors and asking the doctors, or the people that work in the doctors office that handle the insurance forms and all, discussing with them, is this covered, is that covered, what does this mean, what does that mean. We got a lot of information that way.

My doctor tells me. My doctor told me, you know, I asked him that question. There was this sort of controversy in '98, if a doctor took a paying patient and then if he took, if I want to pay for something that Medicare doesn't, then he could lose his license. Not his license, but he couldn't take another Medicare patient for two years. I asked him all about that and he explained it to me.

**Whether medical providers are important sources of information seems to depend more on the provider than on the beneficiary**

I don't find that I've gotten much information from the doctors and nurses, because I don't think that they really know too much about it, you know, the workings of it.

Participant: As many times as I've asked doctors about information on Medicare, they say, see the nurse outside, see the receptionist, you know.

Moderator: Okay. So they refer you to somebody else.

Participant: To someone else who really doesn't know.

## **RADIO, TELEVISION, AND NEWSPAPERS**

Participants with hearing loss were very similar in their rankings and comments about the mass media to those in the general population and most of the other subgroups. They ranked the mass media lowest in trust. Participants who mentioned mass media positively specified particular publications, like *The New York Times*, *Consumer Reports*, and medical newsletters.

**Hard-of-hearing beneficiaries' view of the mass media was similar to that of general population participants**

I never got anything useful out of radio, television and newspapers. They have no practical application to me. . . . I've read things, but I have never felt anything was — particularly applied to my situation. They were all very general.

This journal information, from television, reading the newspapers, my AARP magazine, I pick up any changes, but as I say, I haven't had any problems, so I really haven't had to make any referrals or have made any calls.

Radio, television and newspapers. They are so far off base, particularly lately the TV. People want to be experts on everything and guide. And they are least informed in regard to the facts. You've got to stick with your friends, family, doctors, insurance companies and stay away from the propaganda, or you'll never get anything straight.

Well, I think — I agree on radio and television as being bad sources of information on something like Medicare because those guys have only got so many seconds to tell you what you're — but I've gotten a lot of good information out of health newsletters, Mayo Clinic newsletter, and sometimes periodicals like *Consumer Reports*, every once in a while will do extensive articles on health issues. And those are quite good and quite accurate, I would say.

Well, you get information. I don't know if I'll always trust it. I'll read it and I save it. Radio and television, I don't get much, but newspapers I've learned a lot. And right or wrong, I've learned a lot of information from them.

I think that the Harvard newsletters or the Mayo Clinic newsletters are extremely informative and I belong to the Harvard newsletter so I get information which is accurate. And I think it's an extremely worthwhile type of health letter.

## THE HEALTH CARE FINANCING ADMINISTRATION

As did other participants, those with hearing loss indicated they didn't really know what government agency ran Medicare. They ranked HCFA as the second highest source for trust; as mentioned earlier, the gap analysis indicates that the participants with hearing loss would be receptive to receiving more information from HCFA. Several participants who had read Medicare publications found them hard to understand.

One group had a discussion about how Medicare could improve its communications with beneficiaries, including simplifying the language of publications, a Web site, and improvements in handling telephone calls. When the moderator prompted them that there were other places they could call who were perhaps better equipped to deal with people with hearing loss, they responded that they weren't talking about just hearing loss issues, but about issues of concern to all Medicare beneficiaries.

<b>Participants with hearing loss were generally unaware of HCFA, and many were also not aware of receiving information about Medicare from the government or found the information hard to understand</b>
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The Health Care Financing Administration, because I don't know — wasn't even aware that that was the organization.
--

Right, and I will say this. I have never received a good series of information from Medicare, ever. I get excellent annual ones on Blue Cross, quick things, but I do not have any pamphlets at all on what is my current coverage under Medicare.
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I started out, when I became eligible, my wife and I, we got the books from Medicare. And we read the books, not very clearly. We really don't — we read them. We thought we understood them, but there were a lot of questions. Calling Medicare and asking them the questions does not solve very much. We get better information and found out what it was all about by talking to other people that have been through the process. And we gained from their experience. Also in visiting doctors and asking the doctors, or the people that work in the doctors office that handle the insurance forms and all, discussing with them, is this covered, is that covered, what does this mean, what does that mean. We got a lot of information that way. So basically, we learned about it through other people, neighbors, friends, relatives, and the doctors office. Very little from Medicare itself.
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Participant: I think — well, actually I haven't tried, but I've got the government, what's it called here, the Health Care —
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Moderator: Health Care Financing Administration.
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Participant: Yeah, right.
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Participant: You've got them down on the bottom.
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Participant: I never have used them.
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## **SUPPLEMENTAL INSURANCE COMPANIES**

Participants with hearing loss ranked their supplemental insurance companies very similarly to the general population groups. Several mentioned that they get regular information about claims and that they contact their supplemental insurers by telephone or mail with questions.

<b>Supplemental insurance companies are important sources of information for some participants with hearing loss</b>
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I am satisfied with... the health care [information] Medicare sends forth to me. And then I go to my supplemental for information all the time which is also based on my retirement... These are the only two that are really important to me.
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Moderator: Okay. What was your second choice?
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Participant: My supplemental insurance company.
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Moderator: How [do you get information from them]?
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Participant: By phone or by writing. By phone they are very responsive.
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## **COMMUNITY RESOURCES**

Participants with hearing loss ranked community sources almost identically to the general population. Despite the low ranking (last in amount of information and next to last in trust), several participants, particularly in one group in Maryland, talked about community resources that they knew of or relied on heavily.

**Several hard-of-hearing beneficiaries reported getting information from community sources**

Actually, I have not needed any information, but I'm a member of a senior citizens center in Baltimore. And they have people down there that are trained to get information like a lot of us need, senior. And if I had a question about Medicare, that's where I would go. And I believe I could get it answered there. They also disseminate a lot of folders, a lot of books. I'll tell you, man. I don't want to have to research any answers to Medicare. They got a little red book, white book down there. That's not for me. I want somebody to give me an answer, you know, without me doing all that work.

Well, I go to [a senior citizens' center]. And once a month they have somebody from Blue Cross/Blue Shield and Medicare there. They'll help you as much as they can. In other words, they'll go through your papers and your claims and they'll help you as much as they can.

[A local university] has a whole section for hearing impaired. They have audiologists and all that.

Some of the hospitals or community colleges send out regular monthly newsletters, especially hospitals. And they will have different — and they will list their groups, support groups, that they have that you can attend, hospitals and community colleges.

Yes, I think that the senior citizen center, they have panel discussions there with doctors and nurses or somebody, health care organizations and you can ask them questions. And I think that information is, and it's usually something where they have a panel discussion or some specialist that is, you know, like an eye doctor that would give you information.

**ORGANIZATIONS SUCH AS AARP AND MAGAZINES FOR SENIOR CITIZENS**

Participants with hearing loss ranked AARP highest for amount of information about Medicare, and also high on trust. A number of the participants belonged to AARP, and a few mentioned other magazines as being helpful.

**Participants with hearing loss relied heavily on AARP for information on a variety of topics**

This journal information, from television, reading the newspapers, my AARP magazine, I pick up any changes, but as I say, I haven't had any problems, so I really haven't had to make any referrals or have made any calls.

Reading their publications so I learned more about Medicare from that... than anything else.

Yeah, I'm not sure what other people listed as their top two but I have 'H' which is, because I get information from AARP. Which I consider reliable. And the latest bulletin that came out kind of clears up some of this thing that all went into effect about contracting with your physician.

Moderator: How about information about supplemental insurance plans. Would you like to be able to get that kind of information by computer?

Participant: I would think that you would call the AARP and have them send you a brochure which would give you all the information possible, which they will do very readily.

## HEARING HEALTH CARE SPECIALISTS

Participants who rated hearing health care specialists highly for amount of information were thinking only about information related to their hearing loss. Participants did not get information about Medicare from these specialists, in part because most of their hearing-related needs are not covered by Medicare.

### Hearing-Related Consumer Organizations

Although many of the participants belonged to Self-Help for Hard-of-hearing People (SHHH) and other consumer or support-type groups, these organizations were ranked reasonably low on information about Medicare. Beneficiaries clearly preferred getting information about Medicare from medical providers, insurers, and AARP.

### Other Sources

Participants with hearing loss mentioned a few other sources, including medical newsletters and the NIH.

<b>Participants with hearing loss mentioned few other sources</b>
On some major health considerations, there are very fine hot lines or sources of information, many of them financed by the NIH, but not very many people knew about it. And I'll tell you, this came up three years ago. And I got the best information I needed on cancer from the cancer calling, where you telephone. And they have TTY's and you give them all this information and they send it to you. But a lot of people don't know that these sources of information are there. I found three other people who needed the same kind, and had never heard of it. And nobody — the doctor didn't tell them about it.

## 4.4 MAJOR FINDINGS FOR BENEFICIARIES WITH VISION LOSS

The card sort exercise was not conducted with focus groups participants who have vision loss. The beneficiaries' poor eyesight prevented them from seeing the cards well or working with them easily. Instead, the moderator recited a list of the potential sources, then asked participants to talk about which ones they rely on and trust the most (and the least) for information about their health and the Medicare program. Although this precludes a direct comparison with the results of card sort exercises in



other subpopulation groups, the comments generated in the discussions of potential sources were similar to those heard from seniors without vision loss.

## **FAMILY AND FRIENDS**

Friends and family are highly important sources of information for seniors with vision loss, even more so than for the general population and most subpopulations. Beneficiaries with vision loss rely heavily, and sometimes exclusively, on their family and friends to pass along information that they themselves would miss because they can't see very well (e.g., information in a newspaper or magazine article). Several participants mentioned that friends and family are particularly diligent about reporting new information related to their eye diseases. Similar to general population beneficiary experiences, a significant number of low vision participants get their information from relatives who work in the medical industry (as doctors, nurses, or insurance company personnel). Unlike in the general population groups, participants with vision loss did not make negative comments about family and friends as an information source. More often, participants said they trust this source completely.

<b>Participants with vision loss often rely on friends and family for information</b>
I also have friends and my sister and brothers, too, that have given me information.
I depend on my son or my husband.
I trust my daughter and my friends.
<b>Often, friends and family supply information that low vision beneficiaries may miss</b>
Where I come from, the family is sort of helpful to me... because all I do now, since I have visual impairment, I depend more and more on other people.
If there should be an article in the paper and my daughter doesn't see it, then a friend will call. A good friend who always read the paper like I used to read it, from cover to cover. She'll call me and let me know about it.

**Friends, family, and beneficiaries with vision loss are all on the lookout for information related to eye problems**

And my brother was talking to his optometrist when I started to come up with the problem with the second eye. And his optometrist mentioned a low vision specialist.

Moderator: Where do you get the most [information]?

Participant: My daughter and some friends who know about my condition.

I get most of my information from my daughter. She's retired now and she keeps up on everything... all the newest things.

And then [my daughter] pulls some information from Johns Hopkins Hospital on her computer in regards to glaucoma.

**Several participants with vision loss have relatives in the medical industry on whom they rely for information**

I have a son that's a nurse and a daughter-in-law that's a nurse.

My daughter, she's an RN and I get a lot of information from her and she works with a lot of the doctors at the hospital and she gets a lot of information from them.

## **INSURANCE COMPANIES THAT PAY CLAIMS FOR MEDICARE**

Participants did not mention insurance companies that pay claims for Medicare as an information source that they either trust or don't trust, nor did they report relying on these companies for a great deal of information. However, several use the 800 numbers printed on the claims forms they receive from these insurance companies, and they assume that they're calling HCFA directly (see "Health Care Financing Administration" below).

## **DOCTORS, NURSES, OR CLINICS**

Participants with vision loss rely a great deal on their doctors, both for health-related information and for information about the Medicare program. Questions about Medicare are generally related to benefits coverage. One participant pointed out that doctors are a good source of information about Medicare because they are the ones getting reimbursed by the program. As with general population beneficiary experiences, however, the amount of information obtained seemed to depend more on the provider than the beneficiary.

**Low vision beneficiaries report getting a great deal of information from medical personnel**

Moderator: Where [have you] gotten the most information about Medicare?

Participant: My doctor's office.

Participant: Doctor.

Participant: I find out a lot going to the doctors. They give you a lot of information.

Moderator: Is that your main source?

Participant: Yes.

Participant: And mine, too.

Participant: Yeah, from the doctor... He said I don't think Medicare pays for anything. You have to buy it. He told me Medicare doesn't pay for these glasses.

I called my family doctor about information about the payment of the frames.

I ask [the doctor] if this is covered by Medicare. I think that's the simplest thing to take care of the changes. Forget the books.

Moderator: Let's say that HCFA decided to cover certain kinds of vision devices. How would you find that out?

Participant: You'd ask your primary care physician. And if he didn't know, he could refer you to an... ear and nose.

Moderator: Where do you get your information?

Participant: I get mine from the doctor.

Participant: Doctor, I would say. They are pretty careful because they are the ones that get reimbursed.

**Not all participants are as enthusiastic about doctors as an information source****Doctors not always trustworthy**

Moderator: Do you trust this source?

Participant: Not always.

Don't just trust one doctor.

**Doctors don't always provide a lot of information**

That's a personal thing, though. Other people may have a doctor who is more expansive with information. Mine was not. Mine was strictly... he saw my vision problem.

**RADIO, TELEVISION, AND NEWSPAPERS**

Some participants with low vision use the media to obtain information. Radio, in particular, is a significant source for those who have difficulty seeing a newspaper or television screen. As in the general population, several in the low vision groups expressed distrust of the media, citing distortion and

bias in the information presented. One person, however, thought it would be helpful for Medicare representatives to occasionally appear on television to explain the program.

**Radio, television, and newspapers are useful information sources for some participants with vision loss**

I listen to the radio, to the television and news, and get information through that.

Moderator: In using media, which is most useful?

Participant: I would say radio and/or television.

Participant: Me, too, radio. I have [radio station] on all day long.

Moderator: What are other sources where you get a lot of information about Medicare?

Participant: The newspaper.

Moderator: Where would you like to see more information coming from?

Participant: I think the media would be good because everyone watches television.

Participant: It'd be nice to have Medicare representatives on TV, you know, rather than the usual media.

**Low vision participants can use some media more easily than others**

Moderator: In using media, which is most useful?

Participant: Radio. Television I can't see.

**Some information provided in the media is worth following up on**

Health information [the media] are pretty good [on].

When my husband reads something in the paper with Medicare or something, then I call Medicare and see if it is something that concerns or interests me.

**The information provided by radio, television, and newspapers can't always be trusted**

With TV, these companies that advertise their products and then always say, this is covered by Medicare. I think, my personal opinion is, a lot of companies are pushing their products, selling them to people that really don't actually need that product. But they are selling it and misconstruing their applications for Medicare help just to do business.

Moderator: So I take it TV is not a source you trust?

Participant: Exactly.

Moderator: Is that a source [newspapers] you can trust?

Participant: Not always.

Participant: It's slanted. The media is slanted definitely.

## THE HEALTH CARE FINANCING ADMINISTRATION

A few participants with low vision said they have "called Medicare" with questions about their claims forms. For some, it's essential that a telephone contact be available since low vision beneficiaries can't always see to read printed information. A participant emphasized that having only one number to call is also important, as it's difficult to search for and dial lots of different numbers.

As in the general population, this group of beneficiaries is receptive to getting more information from Medicare. Many participants already think they're contacting HCFA directly when they dial the 800 numbers on their claims forms. (In fact, these numbers often connect callers to the insurance companies that pay claims for Medicare.) One participant even suggested that Medicare provide information about the existence and availability of assistive devices.

### **Participants with vision loss often "call Medicare" with questions**

I called Medicare to ask them, yes.

Medicare has on the claim forms that they send you, that they pay the doctor. There's an 800 number if you have a question... I think if I wanted information regarding any type of a claim, that that would be a starting point.

### **Low vision beneficiaries would like to be able to easily get more information from HCFA**

What would be nice, if there was one place you could direct all your questions without having [to] dial all those numbers. Once you have low vision, it becomes kind of hectic trying to... get to know all the lines.

I would like for Medicare to have a place where you could call for information [about] these TVs that you can get that enlarges the print.

## SUPPLEMENTAL INSURANCE COMPANIES

There was very little discussion of supplemental insurers as a trusted or prolific source of information. A few participants with vision loss reported that they have used this source in the past.

**Some low vision beneficiaries rely on supplemental insurance companies for information**

Moderator: Anybody else call Blue Cross/Blue Shield for information?

Participant: Years ago I did, but not recently.

I get my information through... the insurance company where I'm enlisted.

Well, if you file for supplemental. Sometimes you get it from them because they let you know if they will pay the supplemental or not.

## COMMUNITY RESOURCES

There was little discussion of community resources amongst participants with vision loss. Those who did mention it said they prefer other sources because they don't feel community organizations have the information they're looking for. As in the general population, low vision beneficiaries didn't appear to think of these organizations as sources of information.

**Community resources aren't a prevalent information source among participants with vision loss**

Moderator: Some of these other sources... like senior centers...?

Participants: I don't think they know.

Moderator: Any other reasons why you wouldn't use these other sources?

Participant: I trust my daughter and my friends.

## ORGANIZATIONS SUCH AS AARP AND MAGAZINES FOR SENIOR CITIZENS

AARP was the only organization mentioned by participants with low vision. A few said this was their primary source of information, but did not provide an explanation.

**AARP is an important information source for some low vision participants**

Moderator: Where [have you] gotten the most information about Medicare?

Participant: From AARP.

Participant: AARP, too.

I use AARP, too. I've gone to AARP. And they give us a lot of information. They tell you, did you know such and such? Well, it was... about Medicare.

Moderator: How would you like to receive information?

Participant: Probably by calling up the company like AARP...

## OTHER SOURCES

Similar to general population participants, beneficiaries with vision loss mentioned former employers and retired employee associations as other important sources of information. Additionally, beneficiaries in these focus groups reported that they often rely on their vision specialists or consumer organizations related to vision loss.

### **Former employers and retiree organizations are also important sources of information**

That's the National Association of Retired Federal Employees, their organization... You get into a group, you have certain meetings, you have certain speakers.

Another source are professional organizations, the... Federation of Retired Teachers, or something. They also send information from time to time... I'm looking forward to getting that. And I know that they will have a lot of information.

Participant: I belong to a retired group of employees. And every year they go to the different insurance companies and supposedly pick the one they feel is going to be best for the group.

Moderator: And you trust that source of information?

Participant: I do, because it's a group I've been with so long.

Mine was I retired from GE. And that was... they suggested a supplemental insurance at retirement... So that's how I found out about my insurance. And I've just been with them since I retired. If I had any questions, I would call them.

### **Vision specialists are one source of information for participants with vision loss**

Moderator: Tell me, how did you find out about Medicare and about the services?

Participant: Right through my ophthalmologist.

Then I asked [my ophthalmologist] what else could I do... and he's given me a type-written letter for different sources of information.

### **Some low vision beneficiaries obtain information from consumer organizations related to vision loss**

[My mother] went to her local... they don't call it a blind association anymore. They call it an agency for the visually impaired, or something... She investigated what they had to offer. And she bought me several things [assistive devices], very, very expensive.

I called the Association for the Blind... After that I did get some information from the... Guild for the Blind.

They have what they call the graduates from the Guild for the Blind. And they meet the first Monday of every month in one of the rooms. And they discuss what's... happening around the country... It really brings you up-to-date... It's very interesting.

I get news from [the Macular Degeneration Society], but never anything about Medicare.

## 5. INFORMATION MEDIA

This chapter describes participants' reactions to and preferences for alternative information media. We gathered rich information about media preferences from participants' descriptions of recent experiences seeking information about Medicare. Furthermore, all three focus group protocols probed for detailed reactions to a few priority media, including the Medicare Handbook, telephone assistance and automated response units (ARUs), and computers and the Internet. The protocols for focus groups with beneficiaries with hearing or vision loss also included discussion of media designed to address their specific needs.

### 5.1 MAJOR FINDINGS FOR GENERAL POPULATION BENEFICIARIES

Focus group participants from the general population of Medicare beneficiaries consistently said they want interactive communication with people who understand and know the answers to their questions.

<b>Preferences for interactive communication</b>
As far as I'm concerned as far as information from Medicare, there is nothing in the world like being able to get on the phone and get a one-on-one conversation with someone. You can explain what is the matter and they can give me the answer that I need to know without all the machines.

### MEDICARE HANDBOOK

Most participants from the general population recognized the Medicare Handbook, although there were groups where relatively few participants said they were familiar with the Handbook. Those who did recognize the Handbook said they generally use it as a reference. That is, they put it away without reading it, but referred to it when problems or questions arose. Almost all beneficiaries who used the Handbook agreed that it provided them with the information they needed in a clear and concise way.

<b>The Medicare Handbook used as a reference</b>
Well, every time we have some question I get the book. That's where the information is.



Participants' suggestions for improvement included adding an index, a glossary, a list of resource telephone numbers, and a list of EOMB procedure codes.

## **RADIO AND TELEVISION**

Most participants from the general beneficiary population rely on the media for some information, but participants were very aware of commercial interests that influence what is presented and how it is framed. Several participants noted that commercial interests and sensationalism that is characteristic of mass media sources can obscure the story.

### **Skepticism about television and radio**

I think most of the information is tainted... You're not going to get what is made to be newsworthy... They are out there selling radio time, television time, they want to peak your interest. They give you half truths... You have to be very, very careful.

## **VIDEOTAPES**

Many participants from the general population had seen videotapes on health-related topics in their providers' offices. Some requested videotapes from their insurance companies. There was some suspicion about the video sponsors, but reactions were generally positive.

### **Videotapes are accessible.**

My doctor... he has the videos right in his office that are on his TV. The videos are played all the time. They are healthcare, all the information. Every time I come in I look to see if there's something decent playing and it's always something.

*Videos may be effective for disseminating relatively specific information and they are likely to be particularly useful for topics for which beneficiaries prefer more interactive communication.*

## **NEWSPAPERS AND MAGAZINES**

Newspapers and magazines were an important information source for the general beneficiary population, particularly for those who are active information seekers.

<b>Newsletters and magazines are sources for proactive information-seekers.</b>
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Another source that I have found to be helpful to me is some of these medical newsletters that come out once a month... You can... get updated on certain diseases and treatments for them.
---

## NOTICES IN THE MAIL

When asked, general population participants said they wanted information to come to them through the mail. However, they also reported that they often don't read the mailed notices they already receive. *Mail notices with distinctive designs will enhance the likelihood that beneficiaries pay attention to them.*

<b>Mailed notices are unlikely to be read.</b>
--

I have a problem with mail particularly the last quarter of the year. For a lot of us it is about 96 1/2 percent junk mail.
---

Moderator: Do you get notices about health in the mail?
---

Participant: I don't read everything that comes. There's so much of everything.
---

## COMPUTERS AND THE INTERNET

In their discussions of computers and the Internet as information sources, participants from the general population generally focused on the kind of information that would be available and ease of use rather than on the medium itself. For instance, quite a few participants were open to using computers for information retrieval, but they also expressed concern about the accuracy and timeliness of the information, the information-seeker's privacy, and the costs to the Medicare program. For the most part, participants said they would rather get answers to their questions from a person than from a computer. *Compared to current beneficiaries, future generations of Medicare beneficiaries will likely be more receptive to and may even expect computer-based information from HCFA.*

<b>Computers are an unfriendly resource</b>
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The more assistance you have like this, the fewer live people that you're going to have in the future to sit down and talk to. I'd rather sit across the desk and talk to someone, someone who knows the system and has the computer there to look up things. I would feel much more comfortable.
---

## **800-NUMBERS AND AUTOMATED TELEPHONE MENUS**

Participants who use toll-free numbers to speak with a human generally had good things to say about 800-numbers. Some general population participants complained about language barriers or poorly trained operators. Most participants disliked automated telephone menus or automated response units (ARUs). When explicitly asked, general population participants preferred no more than two menu levels with no more than three options at each level. Other suggestions from participants included: enforcing short waiting times (no more than 10 minutes); recordings that report how much longer the wait will be; an option to repeat menu choices; and the ability to ring an operator at some point during the automated message. In addition, menu options should be slowly and clearly enunciated and well-defined, and they should allow for easy classification of most information needs.

<b>Strong preference to speak with human operator</b>
Medicare could set a precedent by... letting us talk to a human being or at least only one or two choices to get to a human being.

### **5.2 MAJOR FINDINGS FOR BENEFICIARIES WITH LOW EDUCATIONAL ATTAINMENT**

Beneficiaries with low educational attainment had reactions to communication media that were similar to reactions in the general population focus groups. Both sets of beneficiaries prefer receiving written information through the mail, and both sets are impatient with automated telephone menus. There were some differences between the two sets of beneficiaries. For example, participants with low educational attainment were more likely to report difficulty understanding the Medicare Handbook, and their hesitation to use computers was more often centered on the fact that they would need to learn to operate the machines before accessing information on their own.

#### **MEDICARE HANDBOOK**

In each group of participants with low educational attainment, at least half the participants either recognized or remembered receiving the Medicare Handbook. Several participants had used it to look up specific information. A few people said they looked through the Medicare Handbook when it arrived and refer to it regularly for information.

### **The Medicare Handbook is a reference tool for some**

Sometimes I read the material. It has a lot of information.

Participant: We read it and study it quite often and discuss it together, my husband and I.

Moderator: What kinds of things are you looking for when you read it and discuss it?

Participant: Well, I don't know. Maybe it's when we hear of something or read something in the paper and then that kind of causes us to think is that right or wrong. And then you get your book out and go and try to find out.

Moderator: Have you ever used it to answer a specific question you had?

Participant: Yes, how much do they pay. If they don't pay for hospitalization, you know, how much do I have to pay if I'm in the hospital. That's the sort of thing I have to know.

Others reported that they could not find the answers to their questions, even though in many cases the information they sought is addressed in the Handbook. A few of these participants found the information through their doctors or by calling a phone number provided in the Handbook.

### **Some were unable to use the Handbook to answer their questions**

Moderator: So what kinds of thing have you looked up in here?

Participant: Well, I wanted to try to find some way to assist my mother-in-law in some of her bills that she has at the nursing home. That's not in there. Also, I tried to find out who I could call if I thought there was cheating within the billing system. And that's not in there... [I]t gives you information about a specific thing, but not what you're looking for.

Moderator: Anybody else use the booklet for another purpose?

Participant: I wanted to see what kind of health you could get at home.

Moderator: And did you find the information you were looking for?

Participant: No.

### **Other sources consulted when Handbook doesn't answer questions**

Participant: I had the doctor tell me where to go to get the information.

Moderator: But not through the book.

Participant: No.

More so than in the general population, participants with low educational attainment said the Handbook is difficult to understand. They described it as repetitious, fragmented, and dense. Inventory Report findings confirm that beneficiaries with low educational attainment or low literacy skills have difficulty comprehending ideas conveyed in a written format, in part because they process the information in bits and pieces rather than as integral parts of whole concepts.

### Some difficulties understanding the Handbook

Participant: ...If it's too many pages forget it.

Moderator: So does this [the Handbook] look pretty big, like it's too much?

Participant: Kind of rambles a little bit.

Participant: It's kind of difficult to understand sometimes.

Moderator: And can you say why?

Participant: It's like they keep repeating themselves and you still don't know what they're talking about.

Well, my experience with similar stuff that you get in the mail... They start off at the top of the page telling you all that, that and this. By the time they got down to the middle of it, they're kind of reversing themselves. And when you get to the end of it, it don't pertain nothing to what they said at the beginning... And it's so very confusing, because, let's face it, we are elderly citizens. And it does take us a little longer to grasp things.

I would like it to be more simplified.

I understand some of it, and some of it I don't.

Moderator: Have you found that the information in it was clear and understandable...?

Participant: Sometimes, but sometimes it's kind of confusing and I don't always understand it.

*The Inventory Report found that beneficiaries with low educational attainment rely heavily on information communicated face-to-face rather than in writing. Given such a finding, a short, simple brochure outlining the basics of the Medicare program and containing a prominently displayed collection of telephone numbers to call for additional information may successfully address the information needs of many beneficiaries with relatively low literacy skills.*

## RADIO AND TELEVISION

Like participants from the general beneficiary population, beneficiaries with low educational attainment rely on radio and television for some information. Several participants reported that they regularly watch and trust the information provided by health-related talk shows.

### **Health-related television and radio shows**

Moderator: Is there anything good about getting health information through the radio and television?

Participant: Well, there's some good. A 60-minute house call... gives you information sometimes about medicine or procedures that you didn't know about that is helpful to know about.

Participant: Well, if you watch channel 13, there's a doctor and you can kind of keep up with it.

Moderator: Do you trust the information you get?

Participant: Yes, he's pretty good.

Well, sometimes on talk shows they have like a doctor or nurse that has written a book and tell you vitamins to take and what foods are good for you to help with the colon, whatever else.

Also like their general population counterparts, some participants with low educational attainment were suspicious of the trustworthiness of radio and television reports. Furthermore, a few group members commented that coverage in these media is often superficial.

### **Problems getting information from radio and television**

I think the information should be looked at with a grain of salt. You should look at it, run it through your mind and compare it, then see what other information you can get. Read between the lines.

First of all, they can't give you much information, it's all encapsulated. You just get bits and parts because of the time. TV only gives you so much time and then they move on.

*When considering the placement of public service announcements on radio and television shows popular with seniors, as the Inventory Report suggests, it will be useful to identify health-related shows that are widely watched by senior citizens.*

## **VIDEOTAPES**

Both general population participants and participants with low educational attainment reported using videotapes to get information about health topics. Beneficiaries from both sets of focus groups also expressed skepticism about the motives of videotape manufacturers.

**Videotapes about health are accessible**

It's a 'Health and Home' I got from my daughter. She gave me some tapes and I have them at the house now. I play them and give them back to her... It's a good source.

I sent for a videotape about doing exercise and eating proper food because of high cholesterol and all that.

**Some are skeptical of videotapes**

Some of those tapes can be so beguiling and you can sit there and you're conditioned to believing what you can see, the media. They can sway you, you know.

I have [gotten information from videotapes], but I didn't think it was worthwhile, simply because people were getting paid to say something that they read off of a script that was written by the person that wanted to see the product.

Although some people said they would rather read the information they need than view it on a videotape, others said they would be interested in using videotapes on health topics if they were produced by HCFA.

**A few prefer reading to watching videotapes**

Moderator: What would you think about getting information through a video...?

Participant: That's okay, too, but I would rather read it.

Participant: I agree.

Participant: Yes, me too. I like to read it.

**Interest in HCFA-produced videos about health topics**

Participant: You're talking about videos from Medicare itself?

Participant: On health?

Moderator: They could be, yes.

Participant: I would look at one.

## NEWSPAPERS AND MAGAZINES

There was little discussion among beneficiaries with low educational attainment about newspapers and magazines as information sources. One participant admitted to not reading newspapers, while another said that he finds much to disagree with in the articles he reads. Otherwise, there was no reaction to these media — neither strongly negative nor strongly positive.

<b>Weak reactions to newspapers and magazines</b>
I haven't held a newspaper in 20 years.
I read a lot I disagree with.

## NOTICES IN THE MAIL

As with focus group participants from the general population, those with low educational attainment prefer written information that comes to them through the mail. However, both sets of beneficiaries also complained about getting too much junk mail. They reported throwing away material without looking at it when they become too overwhelmed by mail. A few people thought some mailed information is too hard to understand.

<b>Mailed, written information is preferred by some</b>
Participant: Reading is good. Participant: Yes. You can go back and reread it all the time.
Moderator: If something was sent to you in the mail, do you think you would read it? Participant: Yes, I'd read it. Participants (several at once): Yes.
Moderator: Where would you most like to get [information about Medicare and other health related topics]? Participants: Through the mail.
<b>Problems with mailed information</b>
Moderator: How is [mailed notices] as a source of information? Participant 1: No, no good. Participant 2: It's to the point where you don't want to go through it. You just roll it up and discard it. There's so much of it.
I mean I just don't think it's reliable. It's just so slanted toward selling whatever it is they are selling. I want to approach someone if I want to buy something, rather than have a whole bunch of people inundate me with all this stuff.
<b>Sometimes mailed information is hard to understand</b>
I read it but some of it I understand, some of it I don't understand.
They really don't write it so that you can understand it, they really don't, unless you're an expert with 10 years of college or something.

*Beneficiaries with low educational attainment prefer written materials but often find that available materials are confusing. HCFA should provide brochures and pamphlets at lower reading levels. The Inventory Report recommended a fifth grade reading level.*



## COMPUTERS AND THE INTERNET

Participants with low educational attainment were divided in their enthusiasm for using computers to get information about Medicare. Some liked the idea of being able to access information on a computer, although they admitted they would have to learn how to use the machine first. (Only one person from the four groups with low educational attainment had experience using the Internet.) Other participants were adamant that they do not want to take the time to learn about computers.

<b>Many were enthusiastic about using computers</b>
Moderator: Let's say you have a question about supplemental insurance, how would you feel about going to a computer in a public place to get information about different kinds of supplemental insurance?
Participant: That's a good idea. I think the Internet provides excellent information about health care. That's good.
Participant: I hadn't thought about it, but I think I'd like them to do that.
Moderator: What do you think about getting information about your health through a computer?
Participant: Yeah, that would be neat... There are so many various different people you could talk to, as he says, to get all different types of information in regard to anything and everything.
Participant: The world is at your fingertips.
<b>Some want to use computers but need to learn how</b>
I don't know anything but I'm trying to learn.
I wouldn't mind learning the computer.
I'm computer illiterate, but open to becoming computer literate.
Moderator: It sounds like you would be interested in using computers?
Participant: You're never too old to learn.
<b>A few had no interest in computers</b>
No, I don't. I don't have time and I don't have the money. And I'm not home much. If I want anything, I tell my kids. They do it for me.
Moderator: What would you think about getting something like ... through the computer?
Participant: If it suits the person, yeah. But personally, I don't go for it.

The concerns about computer information that were expressed by participants with low levels of educational attainment were more personal than concerns expressed by general population participants. Many low education participants were worried about learning to navigate the computer, understanding instructions on the screen, or investing their own money to purchase a system that would quickly become obsolete. General population beneficiaries were more likely to mention concerns about privacy, security, and timeliness. None of these issues were discussed in low education focus groups, although some participants with low educational attainment expressed concern about the accuracy of computerized information.

### **For low education participants, barriers to using computers are personal**

#### **Learning to operate a computer:**

Moderator: What would you think if you were able to get information about... how Medicare works through these computers?

Participant: You have to know how to operate one, don't you? What do you do if you don't know how to operate one?

Participant: You need a degree.

Participant: You have to go back to college.

#### **Understanding written instructions on the screen:**

Moderator: What do you think about getting information about supplemental insurance plans through a computer?

Participant: Depends on the language... [I]t's got to be simplified. Anything that comes out of the government, you don't know what it is.

Participant: Oh, it has to be simplified, because otherwise people would discard it.

#### **Investing money in a computer system:**

Participant: [A]fter you get to know your computer, then all of a sudden they come in with new stuff. Then you have to update yours. That's the only problem.

Participant: Plus money.

I don't think that I would like to go to the expense of buying a computer...

### **Accuracy of information from computers was a major concern**

Moderator: How about getting information about personal claims, you know, things that have been sent in, finding out the status, finding out what claims are outstanding.

Participant: I would love to get that. I just don't understand it. I don't know if it's accurate. I can't say, I really don't know. I have no means of determining whether they have submitted the right information or not.

How can you determine if it will be accurate?

If it is a program directly by the governmental agency that handles Medicare, then it would be helpful to hear from them. Not anyone else. I'm sure there's organizations that would check them out. See if they are putting out correct information.

*Ensuring that hard copy and on-screen instructions are simple and direct will allow "computer-eager" low education beneficiaries to take advantage of any Internet-accessible information that HCFA may provide.*

### **800-NUMBERS AND AUTOMATED TELEPHONE MENUS**

Like participants in the general population focus groups, participants with low educational attainment had few positive comments about automated telephone menus. They described bad experiences ranging from

getting disconnected repeatedly to on-hold music that was too loud. Other complaints echoed those raised in general population focus groups — for example, the menus are recited too quickly and are not sufficiently comprehensive. In the four focus groups with low education beneficiaries, only one person was enthusiastic about automated menus.

<b>General drawbacks of automated telephone menus</b>
<p>I think the recorded messages are a pain in the brain.</p> <p>I mean it just takes forever to get where you want to go. By the time I get there I wonder what the question was.</p> <p>Sometimes they talk so fast you can't always understand them.</p> <p>You get disconnected so many times and you know you've done it right.</p> <p>It's everybody you call today is press this, press that, press the other, can you hold and then they never come back, and then they are disconnected.</p>
<b>Menus are confusing and difficult to understand</b>
<p>They don't always have the right questions, either, the question you're waiting to hear for yourself. It's not phrased the way that I would word or understand it, you know? So then I'm back to the first one again.</p> <p>Moderator: What do you think about those menus, are they easy for you to use, hard for you to use?</p> <p>Participant: Hard.</p> <p>Participant: Confusing.</p> <p>Moderator: What makes them confusing?</p> <p>Participant: Because they say push one and you push one and then you get the same thing.</p> <p>But sometimes to me the information that they're telling you on the phone is confusing, you know, for what you're supposed to do. And I get confused with it, very confused at times.</p>
<b>One low education participant liked automated menus</b>
<p>Personally, I'm probably the only one that thinks it's great. It gives you the person in the exact department you wanted. You want billing, you got them. If you want to [make] a complaint, you got them... When you have voice mail, it goes directly to that department. You got an answer.</p>

If they must endure an automated menu, participants with low educational attainment want the number of options to be small (no more than four), the number of menu levels to be no more than three, and waiting times to be kept below 10 minutes. Although several said they are willing to wait longer than 10 minutes if the call is important, others felt strongly that they refuse to wait that long. Some suggested that, rather than sit through an automated menu, they would like to leave a message and have their call returned, or wait on hold after being told about how long the wait might be.

<b>Frustrations waiting on hold</b>
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Participant: It is always possible that when you call up somebody, ‘Hold on our line is busy,’ or have an operator get back to you. Is every company that busy that you have to wait until an operator can get to you? I mean this is unbelievable.

Participant: I got a suspicion that they hire less people and make you wait. It’s a form of disciplining you.

Participant: Well, I think the guys in the top think we’re spoiled.

Moderator: How long will you wait before you give up?

Participant: I don’t wait. It’s terrible.

Participant: I wait ten minutes and I say, screw it and I hang up.

#### **If the call is important, some will wait**

Moderator: What’s the maximum number of minutes you’d be willing to wait to talk to a real person?

Participant: It depends on how important the call was. If you really, really needed to know something, you know, I would wait.

#### **Alternatives to waiting on hold**

Participant: What if they say, just leave your number? Then I can go on and do what I need to do.

Participant: That’s much better.

I like the idea of someone coming on and saying, if you choose to wait for five minutes a person will answer. Rather than punching this and going on forever punching buttons, you may as well sit there and wait.

The participants in one low education focus group were asked to react to specific scenarios involving automated response units (ARUs). Those who had used ARUs for banking or to fill prescriptions said they would gladly use ARU services to order Medicare booklets or replace a lost Medicare card. Others were less willing, citing a lack of trust in this type of automation.

**Some were unenthusiastic about ARUs**

Well, a lot of times you don't think about going and getting all your social security number and you ID number and all that stuff and have it up there, and then punch all that in there. I just don't like it.

Participant: Yeah... not punching in all these numbers in there and then depend on the automatic thing, whatever it is, to do it.

Participant: I don't trust them machines.

Moderator: Why don't you trust the automated machine?

Participant: Well, I just don't know how it works, to start out with. I get frustrated, you know, just going through it. And I might make a mistake, punch the wrong number, and then you have to start all over again.

**Participants with experience were more accepting**

It works real well, because I order refills on prescriptions always that way, just punch in the prescription number.

Like their general population counterparts, most participants with low educational attainment said they prefer to talk to a human operator.

**Human operators are preferred by many**

I'd just rather have someone pick up the phone and talk to me.

I feel like you don't talk to people anymore, you talk to a machine. It's so impersonal... I want to talk to a person, not a machine.

I would rather talk to a person and get my feelings across the way I want.

### 5.3 MAJOR FINDING FOR BENEFICIARIES WITH HEARING LOSS

Focus group participants with hearing loss shared many opinions and experiences reported by their general population counterparts. In both sets of focus groups, participants use the Medicare Handbook as a reference, but had suggestions for improvement such as using simpler language and mailing updated editions to beneficiaries more frequently. Both sets of participants distrusted commercial interests in the mass media, and most reactions to automated menus were negative. There were some areas where hearing loss seemed related to media preferences. For example, participants with hearing loss were more likely to rely on television and videotapes for information, in large part because they can take advantage of closed-captioning. Also, a relatively high proportion of participants with hearing loss expressed interest in learning how to obtain information from computers, perhaps because this is an interactive forum in which they are able to participate more fully.

It is worth noting that focus group participants in all of the groups with hearing loss were drawn from the member lists of a consumer organization: Self-Help for Hard-of-hearing People (SHHH). These participants' membership in SHHH provides them with access to an unusual amount of information about both health insurance for the elderly and issues related to hearing loss. Furthermore, they are more likely

to be active information-seekers compared with participants from the general population or other beneficiary subgroups.

## MEDICARE HANDBOOK

About half of the focus group participants with hearing loss recognized the Medicare Handbook and said they had copies at home. A relatively high proportion of participants with hearing loss obtained recent editions of the Medicare Handbook on their own, in some cases from community organizations they are involved in. Some participants said they kept their older copies of the Handbook, but have not tried to get more recent versions.

### **Many participants with hearing loss found their own Medicare Handbooks**

I'm a member of the senior citizens center and I also volunteer down there. And I have access to all that sort of literature...

Participant: We get a booklet every year... We read that book every damn year on that. Now, don't ask me where we get it, I know my wife comes up with it every year. So I don't know... I think my wife got her copy four years ago and then after she requested it, I think every year since they've sent it out to us.

Moderator: Are you saying that you have to request it to get it sent every year?

Participant: I think the first one she did have to ask for. Somebody showed it to her and she said, I'll get one of those. She called and asked them for a copy of it and they sent one and they've sent one every year since.

I sometimes get a group of them from the Medicare office. If I order them, I can get maybe, you know, 24 of them to pass out.

I did the same thing he did. I called and they sent me one.

### **Some held on to old Handbooks, but didn't search for newer editions**

I've seen perhaps not that issue, but one maybe I've seen four or five years ago.

I have a whole file of Medicare stuff, going back many, many years, and when I first started to become Medicare eligible, which is 13 years now. I have all my stuff.

I had [used the Handbook] back when I realized it was up-to-date, whereas I know it's not up-to-date now so I don't refer to it.

Like the general population participants, beneficiaries with hearing loss said they glanced through the Medicare Handbook when they received it, then used it as a reference tool to answer specific questions. The topics they reported looking up in the Handbook included benefits coverage, interpreting claims forms, and locating Medicare's telephone number. A few complained about how information is presented in the Handbook, as well as in other HCFA brochures. One participant suggested the Handbook contain plainer language, space text more widely, and represent some real situations that beneficiaries face.

**Participants with hearing loss use the Handbook the same way their general population counterparts do**

I kept it more or less — I've read through it, and kept it more or less as a reference point, if I needed something...

Moderator: Did you ever look at it yourself?

Participant: Yeah, but at that time... it was just a curiosity thing. It wasn't that I was seeking any specific information.

Well, when I got it — I'm sure I did get it and they send stuff every year or two — I read it. I look through it to see if there's anything changed or anything new, just to understand it. And then I file it in the file.

**Topics they looked up in the Handbook**

Moderator: What kind of information do you look up in it?

Participant: How you read claims.

Participant: For what you're covered.

Participant: Well, what I've used it for was that I had to get a second opinion on some surgical operations I had from my supplementary insurance and so when I called Medicare, they said, well, you don't have to but it helps.

I read the things that are covered and the things that are not covered.

**Some criticized the presentation of Handbook information**

I read it but after awhile, you know, it's just words running together. It's like reading a legal piece of paper.

You know, it's not the most interesting reading going. I can take it in small doses.

Moderator: The way that the material is presented in those brochures that you've been... do you like the way that they write the material?

Participant: Well, it's a little — of course, it's exceedingly complex, but I do my best to check on the coverage.

### **Suggestions for improving the Handbook**

Well... I hate to say it. It is written by people that write these books and all, and not necessarily people that have the experience, if you know what I mean. A person that has the real experience would write that book differently and more to the liking of what we're looking for, the kind of information we want. A lot of unnecessary words... I mean, I don't say it's a bad book, but there's so much that needs to be done. And it should be reviewed by people that have the experience and know what to put in there, what we want to find out. And it could be simplified, and the space smaller, and be a lot more helpful... they got to do a better job on that book.

## **RADIO AND TELEVISION**

Several participants with hearing loss reported that they get at least some health-related information from television, and that they like this source of information. A few participants pointed out that information from television is usually fairly general, but that it's still useful. As in the general population focus groups, some participants with hearing loss had concerns about false advertising and commercial interests.

### **Many like to watch health-related programs**

Well, our local station... they have a health portion several times a week. And it's very helpful.

Well, I think some of the programs they have, for instance, when they have those panel discussions on a certain condition, and they have doctors and people that, you know, really are involved in giving the health care... I get information that way. And I feel I can trust it.

Moderator: What kind of information do you get?

Participant: It covers just about everything. I was interested in the Parkinson disease, because a member of my family has it now, but they cover diabetes, they had the sign language...

Moderator: So you like getting information about your health through television?

Participant: I like it very much.

### **Sometimes television programs aren't detailed or current enough**

It seems to be more general information about health on TV now. They run special segments. I look at NBC nightly news and lately they seem to be having a lot of little things on health... I mean, it's general information, but it's very helpful.

Moderator: How about getting [information] from television and radio?

Participant: Some, but not very detailed.

I like the TV segments where they have the health. Sometimes they have it maybe a week or so behind what some of the magazines and newspapers have it, though.



<b>Participants are suspicious of television's commercial interests</b>
I like the medical [show] or whatever they have. Sometimes [a doctor] is on, those are fairly accurate and you can trust most of what they say. Things I object to would be medical advertisements that they have, you know, by areas. Even various hearing health groups, they claim that they're going to make your hearing better and all this other stuff. They don't know whether they can do that or not. It depends on the individual.

For most participants with hearing loss, television is still a useable medium either because they can hear it well enough with their hearing aids, or because they have access to closed-captioned programs. Closed-captioning is an important tool for many beneficiaries with hearing loss. Participants in these focus groups discussed the benefits and drawbacks of the service, including their desire to see more programs and even commercials closed-captioned. No one mentioned radio as a source, perhaps because even those with good residual hearing still need visual cues.

<b>Closed-captioning is important to seniors with hearing loss</b>
I have caption on my TV. And I get... I'm not even sure what channel it is, 30 on my TV. Anyway, I get a lot of health, general health information from that channel... And it's captioned. And it's beautiful... I really enjoy it.
That's the next thing I wish they would caption almost everything.
Some of the PBS stations do not have captions and I miss that. I depend a great deal on captions.
Moderator: Are these... programs... usually captioned for people?
Participant: Not the commercials too much.
<b>Problems with closed-captioned services</b>
What I would like to have is a pre-broadcast of it so that when they use the captions, it is up with his speech. Otherwise it's too confusing to hear the voice because I depend on both.
And often the captioning is way behind, like two sentences later.
I object to the, sometimes a music background and the voices don't always come through if you're not having captions.
<b>Radio is not an important medium for participants with hearing loss</b>
I can't listen to the radio at all... In fact, I don't even know if I own one!
<b>Conditions under which television can be heard</b>
Moderator: Can you hear television okay?
Participant: Yes, as a rule... You know, when there's only one person speaking... But if there's a group, any time there is a group, then I have trouble.

*Television is an important medium through which to reach many seniors with hearing loss, particularly if the message is closed-captioned.*

## VIDEOTAPES

Several participants with hearing loss said they had experience with videotapes about health procedures they were considering. Generally, these videotapes were available through their health care providers. Others used instructional videos to learn lip reading or sign language, or watched videotapes that discussed hearing loss. A few participants wanted to get health-related information from videotapes but had difficulty finding any that were closed-captioned. Some participants said they would rather get information from insurance companies, doctors, or in some other interactive way. Unlike general population participants, participants with hearing loss did not raise concerns about the biases of videotape producers and manufacturers.

### **Diverse experiences with videotapes**

Moderator: Has anybody ever tried to get health information from videotape?

Participant: Well, I have the tape... And it helps with lip reading.

Moderator: Anybody got a video on health care that was captioned?

Participant: Yes. I work with support groups at senior centers. And I use videos a lot. Dr. Koop's on hearing aids and some movies, some films about people who have hearing problems. And they work very well. They're captioned.

Moderator: Do any of your doctors or any of the clinics or hospitals that you go to, do they ever sit you down in front of an informational health care video?

Participant: They did for my husband when he had cataract surgery... They had us go through.

Moderator: Has a doctor ever given you a video to take home, for instance, about blood pressure or diabetes management?

Participant: For my husband, they did, he had shingles. He had to look at two videos on the television.

Moderator: Do you ever rent videos about health?

Participant: Yeah, they have one on, a group from the heart. My wife rented it, it's all about cholesterol and things like that.

### **Videotape are not always closed-captioned**

I have tried to look in the library, and I've never found anything that is captioned that I can use.

I've experienced health care videos in the doctor's setting but without captioning and that was a big pain.

### **A few prefer other information media and sources**

I personally don't think that's a good source, because it's one-way. They just tell you a lot of stuff. And that's not what you want. You need a source where there's give and take, you ask questions and get answers, whether it's telephone, letters or what have you. But videos or TVs where the source is coming this way and you can't answer questions, you get lost.

Moderator: Supposing you could get some basic information about your health on a video and then go somewhere if you have follow-up questions. Do you think that might work?

Participant: Well, to me, that gets you back to the booklet. I can go in the booklet and read the booklet.

I don't see any particular advantage of looking at the TV. I can get more information really from friends, insurance companies, doctors and people than I can looking at videos. I consider it a waste of time.

*It is likely that a sizeable portion of beneficiaries with hearing loss would take advantage of HCFA-produced closed-captioned videotapes containing information about the Medicare program and other health-related topics.*

## **NEWSPAPERS AND MAGAZINES**

Newspapers and magazines were not a primary source of information for participants with hearing loss. Some participants receive health-related newsletters that they find useful and informative. A few others didn't like the idea of paying for newsletter information.

### **Health-oriented magazines and newsletters are popular**

I think that the Harvard newsletters or the Mayo Clinic newsletters are extremely informative and I belong to the Harvard newsletter so I get information which is accurate. And I think it's an extremely worthwhile type of health letter.

We get several, like the Mayo letter and the one from California. They are, I think they are most informative.

Well, there are some health reports from the Mayo Clinic that people get, and Harvard. Several from California. And there's one magazine I get free that is called [Remedy], it's very small but very informative...

### **A few dislike the idea of paying for subscriptions**

Participant: Some of it, I pass it off to my wife to read. Sometimes it ends in the garbage but usually they're trying to sell something and I kind of shun away from all that.

Participant: That's what I was going to say, because they always want money.

Participant: Or they give you a little teaser, this is what you can have or this is what is available. But you have to pay for it.

## NOTICES IN THE MAIL

Compared to the general population, there was less agreement among participants with hearing loss about preferences for mailed, written information. Although some participants said they like to “get it in writing” in case verbal agreements are called into question, other participants would rather get information from face-to-face conversations or over the telephone. Participants from both populations admitted that much of their non-personal mail is thrown away unopened. A few participants with hearing loss reported that they at least scan every piece so as not to miss important mailings, and one participant said that first-class postage always gets his attention.

### **There was some disagreement about the best information medium**

Moderator: ... her husband would much rather get the information in writing. Do most of you feel that when you're trying to get new information, do you feel that's the best for you to get it?

Participant: No question... You have to get it in writing in order to be sure... If you don't get it in writing, they're going to tell you, well, you misunderstood or I didn't explain it... So if you've got it in black and white and you say, this is what you told me, this is what you wrote me, this is what I expect.

Moderator: What would be the best way for you to get information?

Participant: The best way is face-to-face.

Participant: It has to be telephone for me.

Participant: Or a written letter.

### **Some view mailed notices as junk**

Moderator: What about when you get notices in the mail, like stuff that comes through the mail?

Participant: It goes in the waste basket!

Participant: Same here... it's garbage.

### **Some examine mailed notices, particularly if they are interested in specific information**

I only scan it and if it's interesting, then I'll read it. If not, I follow his procedure to dump it.

I look at everything very quickly and scan it but a large percentage goes in the junk. I have had a special high interest in long-term health care issues and I look at those pretty carefully because of a particular concern in that area.

My experience has been some of the important mail, it really is important, comes bulk rate such as things from securities, informing me what their profits were and so I look at everything before I throw it in the garbage.

### **First-class postage gets attention**

Moderator: What would it take for you to open it and read it?

Participant: First-class postage.

## **MEDIA AND TECHNOLOGY SPECIFIC TO HEARING LOSS**

The Inventory Report described beneficiaries with hearing loss as generally unaware of assistive devices such as telecoils. The Inventory Report also noted that beneficiaries with hearing loss generally lack strong support networks. As members of the consumer organization Self-Help for Hard-of-Hearing People (SHHH), these focus group participants with hearing loss have access to an extensive support network and are fairly well-informed about the technologies available to them. Most of them rely on hearing aids, telecoils, or similar equipment. A few participants provided creative examples of how they took the initiative to facilitate communication.

### **Participants with hearing loss found creative ways to facilitate communication**

There is one thing I have tried a couple of times. And that was when the person with whom I was talking had a computer on the desk, I asked to use the monitor as a captioner, and the person to type it, so I could read it... It was very effective.

I am taking a class... in sign language. And I had difficulty understanding the teacher. And you, at SHHH, had provided me with a hearing device. And I gave it to the teacher. And I have one. And I am able to understand her directly. There is a problem with other people... but I do hear the teacher much better.

*Given the relative isolation of many seniors with hearing loss, HCFA could position itself as another source of information about the existence and availability of assistive devices for hearing loss.*

## **TELEPHONE CONVERSATIONS**

According to the Inventory Report, the telephone is a relatively useless communication vehicle for seniors with hearing loss, particularly since many of them don't take advantage of assistive technology. Among beneficiaries with hearing loss who participated in these focus groups, however, most reported that they do use the telephone, albeit with varying degrees of success. Some rely on friends or family to get information over the telephone; others have amplification devices or aids such as text telephone (TTY); a few can use the telephone without any devices or with the help of their hearing aids. Using the telephone posed some obstacles for these focus group participants. Participants reported problems, ranging from voice quality and volume, to operator insensitivity, to poor interface between their assistive devices and telecommunication technology. Some participants reported difficulties locating TTY numbers on Medicare forms, some have been unable to get through on Medicare TTY numbers because no one answered, and some have encountered customer service representatives who couldn't type, or who talked to the relay operator instead of the caller.

### **Diverse ways to use the telephone**

I do manage because I have a daughter-in-law who does most of my phoning for me...

Well, I've done this. I've asked my wife to call... for me and get the information and tell me what I'm supposed to know.

I got a TTY about six months ago. And I'm very happy with it. I haven't had any trouble. I get my messages without any trouble.

The telecoil has helped a great deal on the telephone, because I can [adjust] it. It cuts out all that extra noise.

I don't have any real problems on the telephone since my telephone is amplified. And I have one ear that's not too bad.

### **Difficulty using the telephone depends on features of the conversation and the technologies used**

[Telephone conversations are] a big difficulty for me. Very often people are either speaking on cordless phones or they speak very fast or they speak indistinctly. And sometimes when I have to call for information I cringe. I think, how am I going to be able to hear this person. Am I going to be able to understand them? Very difficult.

My hearing loss isn't too great, but the one problem I may have is if someone speaks with a foreign accent, and then too fast.

Well, ordinarily I can handle phone conversations all right. However, these people who speak very rapidly, or the people who speak very softly, I can't handle. The rapid speakers I can tell, I'm hard-of-hearing, slow down. The soft speakers don't usually raise their voices.

I do have great difficulty, even with amplification... Also, I've found sometimes it's trouble with the other end, if the telephone is so bad. My broker, especially, has one of these things that you don't have to hold [speaker phone or headset]. [I tell him to ] get off of that thing and get onto your — I can understand you better.

My answering machine is hard to understand, because people do not speak distinctly into it.

### **Difficult experiences with TTY and relay services**

I have TTY and I have trouble with that... because often they... may list... a TTY number, but then you call it and they don't answer it.

First of all, Medicare never puts a TTY number on its papers. And so I have to rustle around and find it... Then I will also go on to say that... I have felt many of the people who answer, in both Medicare and Blue Cross, are not responsive very well to a TTY user. They're suspicious at times... They keep asking you to repeat, and then they do not talk to me directly. They talk to the operator. They tell her this and that and the other thing. So you feel you are begin going around, instead of the direct — they haven't been trained in using TTYs.

And sometimes they have awful spelling and can't type, so you can't figure out what they're doing, particularly if they're giving you numbers on anything. You have to go back — to get a number on a claim, there's a long one, you sometimes have to check that three times to be sure you have it accurate.

Then I do use the relay. And then... the relay person has to get on. And the relay person will run into all these blasted push buttons, recorded announcements. They have to give a rendering to me of the recorded messages. And by the time they do that, we get cut off, and I have to start all over again.

Unlike most seniors with hearing loss, few participants in these focus groups seemed embarrassed to admit or talk about difficulties related to their hearing. This may be in part because SHHH strongly encourages its membership to tell people of their hearing loss as a way of producing more fruitful interactions. Several participants reported that they will tell the operator they are hard-of-hearing, and then ask them to slow down and speak more clearly if they can't hear what's being said. When this doesn't work, some will call back later hoping to get another representative, or will simply give up. A few participants did say they feel uncomfortable asking other people to change their behavior in order to accommodate their hearing loss.

### **When they can't hear, some try other avenues to obtain information**

There have been times when I have said thank you very much and hung up and maybe ask someone else to call for me, to get the information.

Moderator: Have you ever tried to get information on the phone and given up because you couldn't hear?

Participant: I give it to someone who lives with me, even before. If I am having a very important conversation, I always ask them to be alert that I may call them to get information, but I would never hang up without getting information that was needed.

These people who speak very rapidly, or the people who speak very softly, I can't handle... And commonly I [hang up] and hope to get a different operator the next time I call through.

### **Some give up if they can't hear**

When I get a message, many times, I can't understand what the people are saying... I keep repeating the message and repeating it and repeating it. Sometimes I get it and sometimes [if] I don't, I just forget it. I figure if they want me they'll call back.

Participant: Every once in a while somebody just won't speak up on the other end. I've given up, but it's rare... I say that's fine and I hang up.

Moderator: And so then you don't get the information.

Participant: That's right.

### **Some with hearing loss are embarrassed to discuss it**

There's only one thing that bothers me, just to mention it. If I can't hear somebody, I feel embarrassed. I don't like to say to somebody, please speak up. I'm hearing impaired. Would you speak louder. I feel uncomfortable, because I'm putting the burden on those people.

I get embarrassed, too, when I have to get people to repeat and repeat and repeat. And sometimes I say I'll just have somebody call you later.

Despite these obstacles, the telephone is often the most convenient way to get information. To improve the situation, some participants suggested that HCFA dedicate a few operators to beneficiaries with hearing loss. These operators would be trained to modify their speech and to be particularly sensitive to the needs of beneficiaries with hearing loss. One participant mentioned the Treasury Department as an example of an organization that has done this successfully.

### **The telephone is often the most convenient way to get information**

Moderator: What would be a better way for you to get information?

Participant: There is no better way. I mean, if you have to call a company that's in another part of town, you can't very well go over to see them. You just simply have to rely on the telephone. You have no choice.

### **Suggestions for improving customer service to callers with hearing loss**

I have at this point to say I think everyone that has to communicate with people with a hearing loss should take a course in how to speak correctly.

I... rely on my wife to get the information that I need. Maybe [if] they have people that understand the hearing problems of people, people would slow down and talk a little clearer. Maybe that would help more.

If in Medicare they got into this aspect for the telephone of getting a trained person, that doesn't mean that they just get somebody and tell them slow down and take it easy and try to enunciate. They should get a trained person that has some experience with hearing problems, people with hearing problems. And to do the job right, because there's all kinds of follow-up things that could come up that the average person just slow them down and enunciating isn't enough. And they got to be able to handle it. And you get into sensitive areas where people get upset.



<b>Concerns about the quality of information provided by telephone</b>
For me the problem is finding the right person. HCFA is such a big place that the employees there don't know who does what.
I'm not just talking about knowing how to talk to hard-of-hearing people, but people who are knowledgeable in the subject matter.
<b>An example of government efforts to respond to the needs of people with hearing loss</b>
Now, some organizations, like the Treasury Department... I'm always calling them. You end up — you go directly to the person you want. And that person speaks slowly, answers your questions, they do a wonderful job handling the hearing impaired. And I can do her without the relay. So they've looked into this evidently, and I guess a lot of older people have these treasury bills and they want to take care of them or something. But they're a good example of what can be done if other organizations, particularly Medicare, would do more in this area.

*HCFA should make the Medicare TTY number more visible, and ensure that its TTY operators are well-trained and responsive.*

## FACE-TO-FACE CONVERSATIONS

Participants with hearing loss said they prefer face-to-face conversations because they can lip read at the same time that they're trying to hear what's being said. A few participants with hearing loss said they often bring devices with them to help amplify conversation, or ask people to speak up. None had ever been offered an assistive device by the organization they were visiting.

<b>Face-to-face conversations facilitate lip reading</b>
I feel... you get a bonus when you are face-to-face. You are able to do a little speech reading when you're not sure of what you've heard, you know. And you can get the person's empathy, you know. You've let them know that you're — if they don't realize that these are hearing aids, you know, that I need all the help I can get... So I prefer face-to-face.
Well, I find that if you're face-to-face you automatically begin to watch their lips and get an idea of what they're saying by their lips. You know, when they're speaking, when they're talking.
<b>Ways to take advantage of face-to-face conversations</b>
Well, what I do, I got myself a little hand mike. And it attaches onto my hearing aid with a boot. And I just pull that thing out and put this microphone right in the person's face. And then I'm fine.
I talk with them and I ask them to slow down. Not talk too loud and a little bit slower and then I get on with them better.

*HCFA could encourage its state carriers to have assistive devices available for beneficiaries with hearing loss who come for information in person.*

## OTHER MEDIA

A few participants with hearing loss mentioned that they would like to get information from seminars, particularly if the lecturers are amplified. General population and some other subgroup participants also expressed a desire for this type of interaction.

### **Interest in seminars and panel discussions**

In [my city], the hospitals run a series of lectures on health open to everybody... And there is no trouble hearing them because they are well amplified. And if you have any trouble hearing it, they will give you [an assistive device].

The senior citizen center, they have panel discussions there with doctors and nurses or somebody, health care organizations and you can ask them questions. And I think that information is, and it's usually something where they have a panel discussion or some specialist that is, you know, like an eye doctor that would give you information.

## COMPUTERS AND THE INTERNET

Compared to the general population participants, many participants with hearing loss either: (1) already use computers and the Internet, or (2) are interested in getting information through computers. These seniors liked the fact that they could obtain some information interactively through the computer. However, like those in the general population, beneficiaries with hearing loss were also concerned about keeping their personal information confidential. Those who were not as interested in computers as an information source said that it's just as easy for them to get what they need over the telephone or in writing. They also felt that many of today's seniors would benefit less from computers than will future seniors.

### **Many already use a computer regularly**

[I could get information] through the Internet. And I get an awful lot of information from Beyond Hearing, that list, you know...

She and I already have that. We live in a retirement community that has a computer room. And we both are on e-mail. We both use e-mail to write to our relatives and get the information.

I like the computer idea. I have a computer. And I go on the web for all kinds of information, real estate, financial, sports, everything.

The Internet is probably the best source of health information... because they have digests there telling you, if you're looking for the fact that you've got a bone spur, you're going to look up bone spur and it will tell you the whole story about bone spurs... They all have a lot of information that you can't pick up elsewhere.

If [you're] not on the Internet, you're not with it!

I've taken a couple of short courses on the computer and I just don't feel like I'm that proficient yet. But if I could use a computer, I think there's a lot on the Internet that would be very helpful.

### **Many non-users are interested in this medium**

Moderator: How about if information was made available to you on the computer?

Participant: I just want to say yes. I don't have a computer. I don't have enough brains to know how to work one of them, but my daughters have these computers, and this e-mail. They write back and forth the e-mail. So I think it would be wonderful if you taxpayers would pay for these different government agencies to have a system whereby they could send out information to those who have e-mail receiving sties.

I don't really need any information, but if I did, [computers] would be the best way to get it, for sure.

As long as they could make it simple enough in a library so you could figure out what to do. I can't get anything out of my local library on my computer. I get stuck every time I go in there.

Well, I feel if you like to be interactive, so I think if they had somebody on-line that we could talk with, we could tell them and have an answer right back, that would be... great...

Moderator: Let's say the Health Care Financing Administration set it up in such a way that you could get this information over the Internet...

Participant: I would have somebody who's more familiar with it do it for me because I think they could follow through better on that more general information than what I perhaps would do. Go in more detail.

Participant: They have to have enough people involved to answer your questions and not, like on the telephone, put you on hold. I mean, I don't know how it works. But surely they would have, if you have, you know, an individual problem.

I would use it, I would use the computer if I could get a print-out of what they've told me, you know.

**Some are concerned about privacy**

I would not care to, more like bare my soul if too many are going to be reading that.

You know, I wouldn't want everybody privy to what I'm talking about.

**Several prefer other media**

I might get them [HCFA] on the phone. I don't see why to go out and use a computer.

If it's available by the telephone, an 800 number, I would not use it, the computer, to do it. And right now the 800 number is so satisfactory, I get the specific information that I want, I would not use a computer even though I have one.

I would think that you could call the AARP and have them send you a brochure which would give you all the information possible, which they will do very readily.

I just feel that most of us are senior citizens who do not use a computer and I think calling directly is, by far, the best way.

I think it's much more readily available by telephone to have them send it to you. This way you'll have it.

**A few said that their age group is too old to learn computers**

I don't think many of the seniors that I meet with would [use computers]. Maybe younger, a little younger, middle age.

I think it could be helpful in looking towards the oncoming generation, particularly the baby boomers who are now moving into this. I think it's a very, very important information source.

Moderator: Would you [use computers]?

Participant: No.

Moderator: Why not?

Participant: Well, maybe I'm not in need. Maybe I don't feel the need for the information right now. I think I'd get it another way.

Moderator: How about you?

Participant: No, because I don't have anything to do with computers or the Internet... I'm too old to start learning a computer.

Moderator: How about if somebody taught you how to use it, and it was very easy to use?

Participant: No... I've lived long enough without it.

Yeah, I think it's a good source for people who are familiar with computers. I'm like someone else in here. I have a computer, but I haven't mastered it. I have abandoned it.

### **A few participants made suggestions for putting Medicare information on the Internet**

If they had a place [on the web] where you could get information on Medicare, it would be wonderful. But the information has to be written correctly. If they give you pages out of that book, or something, forget it. What has to be done is some research by you people or someone and putting together the right information, and they don't need any more than two pages of what people really want to know, or refer them to where they can get further information...But I think it's a great idea... [I]t could pick up on e-mail and go back and get more information. It would be the best thing they could do, if it's done right... [which] means to me that the person that's going to write this information up for the computer has to spend some [time] talking to people like us and write it up from the point of view of the recipient of Medicare, not what the government or whoever is running Medicare thinks it should be, that this is given to some young, very intelligent person, but has no real experience with what we want and what we need... The information has to come from people like us. And it almost has to be written by us. They got to find out what we want, what we need, and supply that. And then it will be successful.

### **800-NUMBERS AND AUTOMATED TELEPHONE MENUS**

Like participants from the general population, participants with hearing loss were frustrated with automated telephone menus. Those who described satisfactory experiences with 800-numbers were usually able to speak with a real person relatively quickly. Participants with hearing loss reported using the same trick their general population counterparts do — they pretend they have a rotary phone so they can talk to a human. Specific complaints about automated menus were similar to complaints reported across beneficiary populations: the menus are recited too quickly and callers have trouble identifying menu options that address their specific needs. In addition, participants with hearing loss have problems with automated menus and telephone conversations that are related to their hearing loss. The danger is that, out of frustration, beneficiaries with hearing loss will stop pursuing requests and end up not getting the information they need.

### **A few described positive experiences with 800-numbers**

The other day I called three 800-numbers and I got a polite response from all of them. They took my name and address and sent useful information.

It's been awhile since I've called the Medicare on the 800-number, but the last time I called, it rang twice and somebody picked it up and answered my questions.

And right now the 800-number is so satisfactory, I get the specific information that I want...

### **Many have problems using automated menus**

[I]f you have [a menu] that says if you want to repeat this menu, press one or something, then sometimes I have to do that more than once to get the whole menu... Fortunately, a lot of times, the choice I want is the first one. So I push that number and don't miss all of it, but in the occasion I have listened to all of them, I have trouble and I have to punch the button to repeat it.

[T]he biggest disaster is you get a computerized phone and says if you want this push two, if you want this push four, push five... I'm just lost on that. So if I find that is what I'm running into, I have my wife make the call. And even she gets annoyed because she bounces around. She hears well, and finally, she gets through and then she's got to ask me, okay, I got the girl, now what did he say? What do you want? And maybe I'll tell my wife and she can put it through, or I'll make an attempt with the girl. And usually the person is well trained for what the need is, and they slow down and they try to be helpful, but getting to the person through the push buttons is the disaster.

[The automated menus are] unsatisfactory... Because you're told to wait or they give you numbers and you punch out numbers and it's, if you're lucky, if you get to talk to a human person, you know, and that doesn't happen often.

### **Some problems are related to hearing loss**

I just want to tell that I use TTY all the time. And I frequently run into the menu thing. And I thought you'd like to know that even the communication agents who are trained people in the relay service often can't [keep up with] those message either. They can go too fast. I was calling somebody and they had nine different options. And she... just ran out. She said I can't do this. We had to go through the whole thing — this is the trained operator, not my defective ears — three times before she could get it out.

When they say those numbers, you can't hear just what they've said and they're all finished with it before you can really think what it might have meant, you know. It's a kind of, interpret what they've said, it's a problem with the numbers.

### **Participants try a variety of ways to connect with an operator**

My problem is that I have a rotary phone. And so I have to go through all that menu. And then finally they say if you want a human being hold on.

I have a rotary phone, too, but some people with a hearing problem, even if they have a push button, deliberately wait through all the way because they cannot understand the voices on that thing. So they want, listen all the way through until they say if you have a rotary phone, the operator will be with you in a few minutes. So I just have to wait through all of that.

Who doesn't have a problem? Yes, indeed, I do. And so I usually go wait for the operator. Occasionally I can handle it but most of the time I like that one-to-one conversation.

If they say that someone will speak to you if one of the numbers doesn't answer your question, then I just wait.

[U]ltimately, I just wait for the, for someone to come on line because they do rattle them on so fast, I can't interpret the numbers and with regard to what. So I just hold off and sooner or later they come on.



### **Some give up in frustration**

Participant: Sometimes they speak so fast when they go from if you want something you press one, if you want something else you press two. And sometimes I just end up staring into the phone because I end up, I don't really know which number to press.

Moderator: Then what do you do?

Participant: Give up.

Participant: Usually there is some indication there if you want to repeat it. You press maybe the pound key. And I end up doing that.

Moderator: And how many times do you have to press it before you can really understand what it says?

Participant: If I can't understand it by three, I just hang up...Unless it's something that's very important. And then maybe I'll persevere, but usually I will hang up.

Participant: Well, I get very frustrated and if I have to wait more than five minutes, I hang up.

Moderator: What happens about the information then?

Participant: I never get it! Or I wait till the next day or some other time but it's very frustrating. You're standing there with whatever you have in your hand and you're ready to go and it just doesn't happen.

So many of these outfits that use those sort of things, even when we get to the point where you've punched the series of buttons, it's supposed to get you the information, you have a long wait at the end of that... to talk with somebody. And sometimes I just give up and try it at a different time. I feel very irritated, particularly in the case of financial institutions that operate that way. I've not had that much trouble with health services though.

*For beneficiaries with hearing loss, in particular, it is imperative that HCFA provide telephone service that allows for quick and easy contact with a human operator or TTY service.*

## **5.4 MAJOR FINDINGS FOR BENEFICIARIES WITH VISION LOSS**

The opinions of and information media used by participants with vision loss were similar to those of their general population counterparts. In both sets of groups, the Medicare Handbook is used mainly as a reference tool; there is some distrust of information that comes from media such as television and newspapers; many prefer to receive written information through the mail; and participants described frustrating experiences with automated telephone menus. Participants with vision loss also had unique needs and experiences. Seniors with low vision want large print materials and audiotaped information to be more readily accessible. They are heavily reliant on a variety of assistive devices, many of which facilitate their independence, and they want more information about these devices. It is important to note that communication preferences are related to levels of vision loss and access to support systems. For example, participants with relatives or friends who help care for them are more likely to prefer written materials. For all low vision beneficiaries, transportation is a major obstacle that can affect their ability to take advantage of some media such as computers in public places.

## MEDICARE HANDBOOK

More than half of the focus group participants with low vision were familiar with the Medicare Handbook, and several still keep old editions of it at home. As in the general population, a few of those who reported receiving a Handbook had read it thoroughly. Most participants either refer to it only when questions arise, or have never looked at it because they haven't encountered any problems.

### **Some don't remember receiving the Handbook; others don't feel the need to use it**

Moderator: Are you familiar with [the Handbook]?

Participant: I get that every year.

Participant: I don't.

They sent a booklet out some time ago, I received that. But I haven't had any reason to get information.

Participant: I'm not familiar with it but I have it.

Participant: I don't remember seeing it.

Participant: I don't have a new one.

Moderator: How many of you are familiar... with the Medicare Handbook?

Participant: I've seen them before but I don't have one.

Participant: I have one but I never look in it.

### **A few read the Handbook thoroughly**

I don't know whether these people all have the Medicare Handbook or not. I have one. I've had it for quite some time. When I first got it I referred to it almost daily to see what was happening.

When I first got it, I read it. My sight was better then. That was quite a few years back and I still have that copy. I'd like to have a later copy.

Well, when I first got it I read everything in the thing. I still have it but have not referred to it in some time now.

Participants with vision loss commented on the Handbook's accessibility. They also discussed its contents. Participants said they want to receive updated versions of the Handbook regularly, and they suggested that the Handbook clearly identify changes in the Medicare program. Other topics participants thought should be addressed in the Handbook were benefits, coverage, and HMOs.

**Concerns about access to up-to-date Medicare information**

Yes, [I use it] just as a reference and that's what I'd like a new one for.

Yeah, I have one at home. I don't know whether it's up-to-date.

When I first got it, I read it. My sight was better then. That was quite a few years back and I still have that copy. I'd like to have a later copy.

**The Handbook should include information about changes in the Medicare program**

Medicare changes every year. Nobody knows what the changes are... [W]hy can't they send out, on a yearly basis, a new Medicare report as to what the changes in it are? Even if they have large print that they can send out to the ones that are visually handicapped, or a regular print that at least we can give it to some member of the family to read to us. As it stands now, no household has a current Medicare pamphlet.

I'd like to have a late copy because laws do change.

Any change that goes into effect in the government and so forth. That should be in there and should be pointed out.

Just send it out once a year. It should have changes or future changes, a pamphlet or a couple sheets once a year.

**Participants want information about HMOs and coverage**

Moderator: What kind of information might you need to look up?

Participant: Well, all kinds, you know, for different doctors and also what you're covered for, because I'm not on an HMO. I'm on Blue Cross/Blue Shield. And a lot of stuff I'm not covered. You don't get dental and all that stuff... But we're thinking about going on an HMO, but like I said, we're afraid. But anyway, we would use it [the Handbook] a lot.

Unlike general population beneficiaries, whose suggestions for improvement usually were confined to content, participants with low vision were concerned about the Handbook's format. About half the participants said an audio taped version of the Handbook would improve their access to the information it contains. Generally, beneficiaries who requested the Handbook on audio-cassette can no longer read or are used to relying on recorded information such as talking books.

**Many low vision participants want an audiotaped version of the Handbook**

Moderator: Is there some form in which you would like to receive this book?

Participant: I'd like to receive it on cassette, if it's possible.

If they want to give us any information, they should do it in a form that we can use, which is like we were discussing, an audio cassette form, something of that nature. Something that's easy for us. Or if someone has some vision, large type, bold print that can be read. So that's my message for Medicare.

A surprisingly large portion of participants with vision loss prefer to receive a printed version of the Handbook. Some of these seniors rely on a spouse or other caretaker to read printed materials for them. Others have enough residual sight to read for themselves. For participants who read, an accessible Handbook must contain large, bold print and strong contrast. Print size and appearance was a recurring theme among low vision participants. Many participants could explain exactly how printed material should appear in order for them to see it. Inventory Report findings also emphasized the importance of large, bold print and sharp contrast in printed materials aimed at beneficiaries with vision loss.

<b>Participants who rely on friends and family prefer a printed version of the Handbook</b>
<p>I'll ask my husband to read it.</p> <p>It's hard for me to read letters that people write to me. I have to have my husband do that.</p> <p>I should say I am very fortunate in that a friend of mine and I have made our home together for years. And she does all the writing and checks, the checks and things like that for me, reads me the morning paper, and so I've been very happy that way, and very lucky.</p>
<b>Low vision beneficiaries who can still read want large print versions of the Handbook</b>
<p>Actually, if some of these publications are printed in large type and in bold print, that probably would be a little bit easier for us.</p> <p>Moderator: And what form would you like it in?  Participant: Big letters!</p> <p>Large print with nice black printing on white paper, no yellow paper, green paper, or red paper, or blue...</p>

*For low vision beneficiaries, HCFA should make the Handbook readily available on cassette tape. In addition, large print versions that contain bold, dark print on a white background would reach a large audience of beneficiaries with vision loss.*

## **RADIO AND TELEVISION**

Low vision participants' reactions to radio and television as information media differed considerably from reactions in the general population discussions. Some participants with vision loss were concerned about the trustworthiness of television and radio information. In general, participants with vision loss were likely to talk about features of these media related to their vision loss. Some participants said they listen to television programs, but many no longer watch television because they can't see what's happening on the screen. For them, radio is an extremely important communication medium. Some rely on radio stations that perform services for people with vision loss such as reading newspaper articles or reciting announcements of grocery store sales. Several participants indicated that they would like access to television and radio programs about vision ailments.

<b>Low vision participants often can't see television images</b>
<p>Moderator: Well, I have a feeling that perhaps people who are visually impaired watch less TV because they can't see it. Am I correct?</p>

Participant: You're right as far as I'm concerned.

Participant: I can see if I sit smack up [against it].

Television I can't see.

### **Radio is an important information source**

Participant: I listen to the radio.

Participant: I do, too. I listen to the radio.

Moderator: So if Medicare wanted to give you a message, or tell you about some new program or some benefit, the radio might be a useful way to get this information?

Participant: The best.

I listen to the radio, and to the television and news, and get information through that.

Moderator: In using media... which is most useful?

Participant: I would say radio and/or television.

Participant: Me, too, radio. I have [a radio station] on all day long.

Participant: I was just going to say, as far as radio is concerned, I haven't heard anybody mention about the wonderful service that we have free... here on the radio.

Moderator: Is that where they read the paper in the mornings?

Participant: Yes... [T]hey have stories, they have all kinds of articles, new magazines. They even do the TV previews.

Moderator: So... less than half [listen to that station]. The people who don't listen to it, are you interested in listening to it now that you've heard about it?

Participant: Sure!

Participant: Yeah.

### **Low vision participants don't always trust the information they hear on television**

With TV, these companies that advertise their products and then always they say, this is covered by Medicare. I think, my personal opinion is, a lot of companies are pushing their products, selling them to people that really don't actually need that product. But they are selling it and misconstruing their applications for Medicare help just to do business.

It's good that they give this information on radio and TV and we appreciate it, but... check it first. Check it out. Before you do anything, check it out. It is a product, if it is some place you have to go, or something, check it first. It's good that they give you the information, but it is up to you to check it before you take any steps about it.

### **Low vision beneficiaries want to hear more information about vision and vision loss on the radio and television**

Moderator: What would you say is good about getting information from [radio and television], and what's not good?

Participant: I would say there's not very much, about the eyesight anyway. To me, you don't get very much. Every once in awhile you'll have a special program on it.

Participant: I don't hear anything about degeneration.

In the last year I've seen more about macular degeneration on TV. All kinds of things. But... I always ask the doctor... or a specialist or someone. Because, as you say, there are a lot of misinformation.

*In planning a strategy for disseminating information about Medicare to low vision beneficiaries, HCFA should keep in mind the importance of radio to this population.*

## **VIDEOTAPES**

Very few low vision seniors reported relying on videotapes for information. Some participants expressed interest in videotapes about vision ailments.

### **Videos are not an important source of information for low vision beneficiaries**

Moderator: What about videos? Is that a medium anyone uses?

Participant: No.

Participant: I don't think there's anything about vision.

Moderator: But if there were, would you use them?

Participant: Yes.

Participant: I think so. If it were something I could help or use.

Moderator: Does anybody use or listen to videos to get information?

Participant: Just for fun.

## **NEWSPAPERS AND MAGAZINES**

Some participants reported that they read the newspaper or subscribe to newsletters put out by senior organizations, groups for the visually impaired and medical research institutes. A few participants with vision loss said they distrust some of these sources. Other participants were more concerned about being able to see printed materials.

### **Newspapers and magazines are important sources for some**

Moderator: What are other sources where you get a lot of information about Medicare?

Participant: The newspaper.

When my husband reads something in the paper with Medicare or something, then I call Medicare and see if it is something that concerns or interests me.

I had read the newsletter that [she] read, from Hopkins. They have a newsletter they send out. And then I found out the same deal in the [organization for the visually impaired] newsletter, so that's where I get a lot of my information sent that I can get read. So that made a big difference.

### **Low vision participants don't always trust information from newspapers**

Moderator: Is [the newspaper] a source that you can trust?

Participant: Not always.

Participant: It's slanted. The media is slanted, definitely. But, for health information they are pretty good.

You have to be cautious about what you hear... I think the newspaper people, in particular, just jump on the bandwagon because they want to be the first one to tell you there's a cure when... much of it is hearsay and much of it is not accurate medically. Or proven.

### **Low vision seniors need readable print**

Eight-inch headlines in the newspaper. I can read those pretty well. Also, bold print, not the regular print, but bold print with my glasses on.

It's easy for me to read a magazine on shiny paper. The print seems much more sharp. Newspaper, I guess they print on this cheap stuff. And I think it blurs the letters a little bit.

Moderator: Does anybody use [newspapers or magazines] as a source?

Participant: Well, it's hard when you can't read! Well, it is, I mean. I mean, you know, you go to all these places, the magazines and papers and everything to get information. It's very difficult. I know that even with the little magnifying card I have on my glasses, it's very difficult for me to read anything for any length, you know. I just about stopped taking subscriptions to anything because I just have to let them stay, put them aside.

## **NOTICES IN THE MAIL**

Many participants with vision loss want to get information about Medicare through the mail. However, beneficiaries with vision loss need support to use these materials effectively. This medium is largely preferred by those who are still able to read with the help of assistive devices, and those with friends or relatives who read to them. Participants without these supports were interested in other ways of receiving information, such as on audio-cassette tapes or at seminars and roundtable discussions. Again, participants who can read on their own emphasized the need for large print materials.

**Participants who can get assistance reading prefer mailed notices**

Moderator: How would you like to get... information?

Participant: I think written literature... We could all find somebody to read it.

[A]nything that I get through the mail, I'm able to read on my CCTV. That's the biggest help to me. Whenever I get anything through the mail from Medicare... I read it on my CCTV.

Moderator: Where would you most like to get your information about your health or Medicare?

Participant: I think printed information... I graduated, about a month's time, past large print. It's not of much value to me anymore. I can read with my magnifiers. And, of course, as long as I have a good and faithful wife, that simplifies my life a lot... But I think for me the printed would be best.

**Large print is essential**

Moderator: Where would you most like to be able to get your information?

Participant: I would like to have it sent to me.

Moderator: In what form?

Participant: Right now, my choice as of today is large print, if anything.

**Participants without support have trouble with mailed notices**

Moderator: If Medicare wanted to give you information, and they sent you a pamphlet in the mail to tell you about some new program or some benefit...

Participant: That would be wonderful.

Participant: Would it be wonderful?

Participant: No. How would it? Could I read it?

Participant: Oh no. You'd have to have somebody read it to you.

Participant: Yeah, but I live alone. I live alone.

Someone who lives by themselves with low vision, it would be hard for them and they would have to give her a telephone call or something, but for me with my husband, it would be okay. Not all people are the same.

Now it's very possible that something has come in the mail, but if it has come in the mail and I cannot see it, I may have either discarded it or lost it. But I would definitely need some kind of oral kind of information fed to me, rather than written information. That's of no use to me.

I just don't read things that come in the mail.

**Many were interested in receiving information on audio-cassettes**

I think probably cassette, something that if I had to listen to a second or third time I could do it that way, and privately. I don't necessarily want to expose my frailties to the world.

Moderator: Where would you most like to be able to get your information?

Participant: I answer a cassette. Then I wouldn't have to read everything.

Participant: I want them on cassette, too.

I would love a cassette. I have a tape recorder in several rooms. And I'd just slam the cassette in, the tape in, and listen to the tape, books on tape, information on tape.

Moderator: What's your preferred way of getting information about Medicare?



Participant: I imagine a tape would be the better way because you do have some machines that would play the tapes.

Participant: I think tape would be about the best for me in there.

A few participants stressed that they want information sent directly to them, regardless of the medium. One reason for this may be that transportation is a major obstacle for these seniors. Even those with involved friends and family prefer not to depend too heavily on these caretakers. This issue was discussed by participants more thoroughly in the section on computer use, but it applies here as well.

<b>An important advantage of mailed information is that it comes directly to beneficiaries</b>
--

Participant: Medicare puts out booklets. The only trouble is that no one picks them up. They don't phone in either to have them mailed.
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Participant: They should just send them when they send those bills.
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Participant: That would be good.
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Moderator: Where would you most like to get your information about your health or Medicare?
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Participant: Through the mail.
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The mail would be best because how many people could go to the office to pick it up?
--

*Although many seniors with vision loss say they still want to receive written information, audio-cassette tapes are another useful medium for these participants.*

## **MEDIA AND TECHNOLOGIES SPECIFIC TO VISION LOSS**

The Inventory Report noted that seniors with vision loss need technologies that facilitate independent living. Focus group discussions with low vision beneficiaries confirmed this finding. Several participants described the central role that assistive devices play in their lives. They emphasized their reliance on assistive devices by listing activities they are able to participate in because of these tools. Unfortunately, the high cost of assistive technology makes acquiring the equipment prohibitive for many beneficiaries with vision loss. Only a few participants had devices such as closed-circuit televisions or high-powered telescopic lenses. Most said they rely on less expensive magnifying glasses, or take advantage of talking book, magazine, or newspaper services.

### **Assistive devices provide independence**

I'm always looking for anything that will sort of help me.

Moderator: But what I'm hearing is that the vision devices that you have are very, very important.

Participant: Yeah. I couldn't function without mine. I could not live alone. And I've always been very independent. And I really could not... I couldn't write my check, I couldn't read my mail. I couldn't function without them. And I really don't use them to read books, because it's too tiring... Just for daily living. If I go to the store to buy groceries, I need a magnifying glass to be able to see what type of an item I pick. I mean, I could pick up a can of corn and open it thinking I wanted a can of beans or something. I do need them for that reason.

Participant: And the last doctor... he showed me a device, it's a closed circuit television device.

Participant: I have that.

Participant: And isn't it marvelous? For the first time in two years... it was such an emotional activity for me that I was able to read Time magazine for the first time in two years, and to do the crossword puzzle.

I can't even read my own name here without it. I got one lens that I use to try to read... It's a magnifying, and it's expensive, too.

Very, very expensive. But I... well, it's something personal with me. Otherwise, I could not read my mail. I couldn't read my prescription bottles... I couldn't read my packages when I'm cooking.

Especially if you were a reader and enjoy reading. It leaves a big hole in your life when you can't do that. So talking books fills that for me.

### **Assistive devices are often prohibitively expensive**

When I was at [the doctor's] office, I tried the machine and it really helped, but it's so expensive.

I did get, through a lot of telephone work, the name of the people that had this device on TV. It was sort of a pair of binoculars, telescopic... So to pursue that a little bit further, I'm supposed to go for an evaluation of this, and then I understand that's supposed to be in the neighborhood of \$4,000.

All this material... because I've gotten catalogues from almost every company that sells blind material and visual aids. And the prices on there is out of line.

Many participants with vision loss criticized Medicare for not covering at least part of the cost of devices that assist vision. Several participants compared their need for low vision assistive devices to that of handicapped individuals for wheelchairs. Barring a policy change however, HCFA may be able to fill an important niche by providing information about the existence and availability of devices. Low vision participants shared information about current technologies and programs for the visually impaired at several points during the focus group discussions. While a few people seemed to have everything

available, others weren't even aware of local talking book programs or radio stations geared to the visually impaired. When participants heard about these resources, they were very interested and asked for more information. The Inventory Report also recommended that HCFA become a source of information about low vision assistive devices.

**Participants with low vision wondered why low vision assistive devices are not covered by Medicare**

There is an 800-number and then they referred me to another department which furnishes wheelchairs and different equipment and that to help individuals who are handicapped. That's where I received the answer for people that are blind and they don't even furnish canes. Why they are excluded I don't know. When you are blind, you, any individual, that is always doing everything themselves, never had to rely on anyone, then when you do have that degeneration, then everything stops and you are a second class citizen. You can't do anything yourself and you're not getting any help.

See, because, with the machine that I am currently using, which I am only renting because it's so expensive, I could actually continue to work. I could actually continue to perform my profession, if I had had it a little bit sooner. So if Medicare can buy a walker, if they can provide a quad cane, if they can provide these materials for people who are physically handicapped, a wheelchair, surely they should be able to provide something for us that we would be able to, you know, live at least more comfortably

**Participants want Medicare to help them pay for assistive devices**

Medicare ought to be able to help more in the line of those type of things like magnifying glasses and handheld magnification.

The little handheld magnifying glass that's lighted, it requires batteries and bulbs. And some of them have plastic handles that break. The first one she bought was \$40. The second time she went it was \$80. The third time she went it was \$125 for that same type of mechanism. So if indeed Medicare could gather all of these materials and kind of set some price limits on what they are willing to pay and what the traffic will allow, well, then, I think that would benefit us all.

**Low vision beneficiaries need more information about the availability of assistive devices**

Participant: What is a talking book?

Participant: Just a tape.

Participant: They're wonderful.

Participant: You mean like novels and so forth?

Participant: Yes, everything. Magazine articles, too.

Participant: And I can give you the telephone number.

Where do you get the large print books?

Participant: May I ask you, how much... did you pay for the Aladdin?

Participant: It was, well, I paid \$2,000 for it.

Participant: You know, you get to the point where you would like to have one but your vision changes so frequently sometimes, until you don't know whether the item you're getting will help you out or not if it got any worse.

Participant: Can I answer that?

Moderator: Certainly.

Participant: They're adjustable. The CCTVs are adjustable and, as I mentioned, up to 60... So if you can manage, you could probably go with a low power and increase it as needed.

*HCFA could fill an important gap by providing information about assistive technologies and services.*

## OTHER MEDIA

Seminars were another popular vehicle for receiving information among low vision participants. Participants pointed out that in seminars they can get their individual questions answered. Some noted that it is important to identify effective methods for announcing seminars.

### **Interest in finding out about Medicare through seminars and roundtable discussions**

Participant: I like [a roundtable discussion]... [with] even more people than this, whatever is feasible, and on a one-to-one basis after the general discussion. But this is the kind of way I could assimilate information best.

Participant: It's very educational to me.

I go to a breakfast for senior citizens and they have all these plans, but it was like, they would just tell you their plan at these different restaurants. But when you talked to different ones, then you find out that... which ones aren't any good.

Participant: On the first Tuesday of each month, a low vision meeting. A lady conducts it and goes through all types of eye exercises and so forth. This is quite helpful.

Moderator: Does anyone else participate in anything like that? Would you be interested?

Participant: Yes.

Participant: Anything we can do to help ourselves.

Moderator: Where would you most like to be able to get your information?

Participant: I say a roundtable.

Medicare should have more information to us, just not in paper, but like have seminars for people. Medicare needs to have more seminars for people to go and listen to them maybe. Maybe that would help.

### **It is important to advertise Medicare seminars effectively**

The only thing this is you would have to be advertised of [the seminars]. Even if it is announced on TV you may miss that particular announcement. Even if it is in the paper, you may not see the article. We have to really be advertised.

## COMPUTERS AND THE INTERNET

Participants with low vision were unenthusiastic about computers. One reason is difficulty seeing the computer screen. One participant knew of a special attachment designed to magnify computer screens — this was incentive enough for him to be interested in using a computer. Low vision seniors also had concerns similar to those of the general population. For example, they had questions about the trustworthiness of information obtained from the Internet, and the difficulty senior citizens might have learning to operate computers. Even low vision participants who already use electronic assistive devices such as teletype machines and talking calculators had reservations about learning to work with a computer.

### **Difficulty seeing computer screens**

It [computers] wouldn't help anybody that had a problem like we do. I mean, I even — when I'm watching television and I'm sitting very close to the television, in order to see it. And when they come on the screen with credits or information that's printed, I can't read that. So that would be impossible.

Moderator: Anybody here computer literate?

Participant: No, I can't... I can't see it.

Moderator: It's a great source of information.

Participant: If you can read it.

### **Devices that magnify computer screens**

Yes [I would use a computer], there is an attachment to a computer, a magnifying attachment that can be used on any computer that will give you the direct source of anything you want. Already approved by the AMA and all that.

### **Concerns about trusting computer information and learning how to use computers**

Participant: How much of it [information on the computer] can you trust?

Participant: They can put anything on the web. I've heard that.

Moderator: What do you need to tell [HCFA] about what your needs would be before that computer could be useful to you?

Participant: You would have to learn how to use it. And how can you do that?... [O]ur age weren't trained to it. It's hard for seniors to learn anyhow, and then to be completely blind, you don't know...

For the low vision participants, transportation is an important issue. In every low vision focus group, participants said they would have difficulty getting to a computer set up in a public place. This fact, coupled with the high cost of obtaining a personal computer (and assistive devices for seeing it), makes this medium unattractive to many low vision seniors.

### **Transportation is a barrier**

Before you're into the computer, you've got to get somebody to take you to the library. And you don't drive with a visual problem. So this is the biggest thing. Do you lose your independence when you do not drive and you do not ask neighbors to take you to the library and go work on a computer. You're lucky if you get somebody to take you to the doctor without access to it... [T]hat is our biggest problem, transportation.

Moderator: Would that be a way [through computers] to get information about Medicare?

Participant: I'd have to get there.

Participant: That's the problem, getting there. There's no transportation.

Moderator: What do you think about getting information about how Medicare works through computers?... They'd be centrally located in places like libraries or senior centers or maybe even Medicare's office.

Participant: If you have transportation to get to those places.

### **Cost is another barrier**

I've used [a computer]. I have interest in one, but just like talking about these magnifiers, the prices, it's like they gouge you or they're exorbitant.

That's what I was going to say about the computers. Who can afford them?

*Unless fitted with expensive assistive devices, it is unlikely that computers will be an important information vehicle for low vision seniors.*

## **800-NUMBERS AND AUTOMATED TELEPHONE MENUS**

Low vision participants expressed many of the same frustrations with automated telephone menus that were expressed by those in the general population focus groups. For example, menus are recited too quickly, the menu options often don't match information needs, and it's difficult to reach an operator. These general problems are compounded by vision loss. It is difficult for low vision seniors to see and use the telephone keypad. Some also have hearing loss, which further contributes to problems using the telephone.

### **Low vision participants generally had negative reactions to automated telephone menus**

What bothers me about those 800-numbers, the menu. Press one if this happens. Press two if this happens. Press 3 if this happens, and that interminable music. I do not want to hear their music. If I want music, I do my own. But the music and those menus.

I'm always confused about if I want number two, should I punch it now, or is that going to cancel the whole thing and I've got to dial all over again. Maybe they could standardize on that. It would cost them so little to give you that little warning or tip to begin with.



**Specific problems include pacing, difficulty understanding options, and difficulty reaching a human operator**

I don't use the phone that often, but when I do, it passes so fast that you have to redial again in order to know what number to press.

I you are blah, blah, blah, press one. If you are blah, blah, blah, press two. And then by the time you get off you're like, I can't remember which one I'm supposed to press.

Well, sometimes you want information and you're not sure what department to go through. I've had that happen several times.

My worst experience was when I was on the phone for 45 minutes and they kept switching me from one to another and to a different menu and back and forth. That was my worst experience.

You punch all these numbers, you punch this and you punch that and you don't know where to go.

The music will play. We'll be back. Hold on please. Music will play. Hold on please. Just for experience, one time I wanted to... of course it depends on who you're dealing with, who you're calling, and the nature of the call. This particular time I'm listening to the music, we'll be right with you. And that kept on. I'm looking at the clock, because I can just barely make out some of the numbers, but it was at least 10 minutes. Like a dummy I'm on there with that phone, just to find out how long does this go on.

**Low vision participants with hearing loss have extra problems using telephones and automated menus**

I have a hearing aid as you can see. I take this one out and I have a power amplifier on the end of my receiver. If I understand everything that they say, I go ahead and punch them. If I didn't understand, I redial the 800 and then try to get it punched.

I'm hearing impaired and I was given a beautiful wall phone, big numbers and you can have it as high as you want, the volume. And it also has a memory thing there.

Another thing I don't like is someone with a very soft voice and you can't hear them. Or, there are people who talk really fast.

As for 800-numbers in general, a few participants described positive experiences. One person avoids writing checks by paying her bills over the phone. Another liked the fact that the numbers are toll-free.

<b>Some reported positive experiences with automated telephone services</b>
<p>I like the telephone, because I pay my bills by phone. I don't have to write checks out. And that is a big help.</p> <p>Well, the best thing about an 800 number is it doesn't cost anything. I've used it for hotel reservations and things of that type, but I've never used it for Medicare. I think Jacksonville has an 800 number, it is on the form that you get back after you visit the doctor and they have paid the bill.</p>

Low vision participants said they are not willing to wait on hold for more than about five minutes although they will wait longer when their question is important. They don't want to listen to more than five menu options at one or two menu levels. One participant suggested that HCFA set up a direct line for visually impaired beneficiaries only. Others want the option of leaving a message for an operator to return their call.

<b>A telephone number designated for beneficiaries with vision loss</b>
<p>Well, if there were a direct number [for people who are visually impaired] perhaps it wouldn't be so bad.</p>
<b>Preference for human operators rather than automated menus</b>
<p>The best thing is if they say we'll take your number and get back to you.</p> <p>I like it better when you could call a business house no matter what it was and an operator would answer at the switch board and you could explain what you needed and wanted and then she would give it to you. This business with this telephone thing and these numbers, oh, it's a nightmare.</p> <p>Well, the only thing that's good is if you can get through to a person! The problem is trying to get through a company and then they give you another... and you got to go to somebody else and then to somebody else...</p>
<b>Some deliberately bypass automated menus to reach a human operator</b>
<p>Moderator: What do you do when [you encounter an automated menu]?</p> <p>Participant: Hold on. They say if you don't have the right kind of telephone, just wait.</p> <p>Moderator: So you pretend you don't have the right kind...</p> <p>Participant: That's right!</p>

## USING THE TELEPHONE

In addition to their experiences with 800-numbers and automated menus, low vision participants described problems using the telephone instrument. They often have trouble distinguishing keypad numbers when dialing, and they can't use telephone directories to look up phone numbers because the print is too small. Some low vision seniors work around these obstacles by purchasing phones with large print keypads, memorizing where the numbers are on the keypad, using preprogrammed buttons, or requesting free information services from the telephone company.

### **A variety of strategies for using the telephone**

That would be great to get a phone with big numbers. My mother had macular, so they gave me her phone. The numbers are that big. And after a while you can even memorize, you know.

Participant: I have a touch phone with large numbers, but then to look in the phone book, in the directory is my problem.

Participant: [I]f you send a record, a letter from you doctor stating your disability... they will not charge you for all the 555-1212 calls.

My brother has certain... it's programmed for me, certain numbers.

I go by feel on the touch phone. Rotary is... the only thing I found out about a rotary, they say if you take a piece of string, and where the hole is for number 4, tie that string around. That gives you a so-called way of determining what number you're calling. You know the 4 is there. You want to go up or below, but on a touch tone, as I say, the way the numbers are arranged, I already know that by feel.

You know what I haven't memorized? The letters.

*Considering the difficulty low vision beneficiaries have using the telephone, and automated menus in particular, HCFA could provide designated customer service representatives for this subpopulation. Such a service could reduce low vision seniors' need for expensive technologies that are barriers to obtaining information.*

## **6. SUMMARY OF FINDINGS FOR EACH OF THREE BENEFICIARY STUDY POPULATIONS BY SUBPOPULATION**

This chapter summarizes major results from focus group research activities separately for each study population. Our focus group research was designed to answer two general questions:

What information do beneficiaries want and need from HCFA?

How can that information be most effectively made available?

We will use these two questions to structure the summaries in this chapter.

### **6.1 BENEFICIARIES WITH LOW EDUCATIONAL ATTAINMENT**

#### **What information do beneficiaries with low educational attainment want and need from HCFA?**

Few participants with low educational attainment understand how Medicare is structured and how the components work together. In addition, these beneficiaries had some general and some specific questions about coverage. They want to know more about the claims process, individual contributions to Medicare, and recent changes to the program. They would like information about these topics to be presented simply and clearly.

Although most participants with low educational attainment are satisfied relying on advice from friends and family to choose a health care provider, some expressed interest in receiving information from HCFA about potential providers' education, experience, and interpersonal skills.

Beneficiaries with less than a high school education need more information about HMOs, particularly information that would address their concerns about quality of care, access to care, and provider choice.

Participants with low education levels want straightforward information about supplemental insurance plans, including plan comparisons, from an objective source such as HCFA. Some would like guidance or advice from HCFA in choosing an appropriate plan.

Participants with low educational attainment often find that messages about staying healthy are confusing. They are not particularly interested in getting information on this topic from HCFA, perhaps because they believe less information would be less confusing.

**How can information be most effectively made available to beneficiaries with low educational attainment?**

Gap analysis indicates that participants with low education may be receptive to getting more information from HCFA. The very large gap between amount of information and trust indicates that "brand recognition," i.e., knowing that information about Medicare is coming from the government agency responsible for the program, is particularly important for this subgroup.

Lower education participants rated medical providers highly for amount of information received, but very low on trust. For some, the lack of trust related to medical care as well as information about Medicare. Others felt their providers are either not knowledgeable about Medicare or wouldn't take the time to talk with them about it.

Low education beneficiaries show a gap between trust in and amount of information received from family and friends, indicating they would like more information from this source.

The gap for mass media suggests that low education beneficiaries would like less information from this source.

Beneficiaries with low education ranked supplemental insurance companies, community resources, and organizations such as AARP low on amount and trustworthiness of the information they provide.

Participants with low educational attainment have difficulty reading, understanding and using the Medicare Handbook. They often described the Handbook as too lengthy, repetitious, and confusing. They might prefer a shorter, simpler brochure.

A few participants with low educational attainment were interested in videotapes on health topics. Several said they watch and trust the information provided by health-related talk shows.

Participants said they prefer written materials over other nonprint media, but they think that available print materials are confusing.

Some participants with less than a high school diploma were eager to learn how to access information with a computer. However, a substantial portion of low education participants were not convinced that they would be able to learn to use computers or navigate the screens.

For those with low educational attainment, automated telephone menus pose problems because options are recited too quickly or aren't comprehensive enough. A few who have used

automated menus to conduct banking or fill prescriptions were more comfortable, even enthusiastic, about having Medicare-related requests filled this way.

## **6.2 BENEFICIARIES WITH HEARING LOSS**

### **What information do beneficiaries with hearing loss want and need from HCFA?**

Focus group participants with hearing loss were more likely than those in the general population to have a basic understanding of how Medicare, insurance companies that pay claims, and supplemental insurers work together. At the same time, they expressed needs for information about coverage for preventive care, dental care, and hearing loss (e.g., why hearing aids aren't covered), the claims process, changes in the Medicare program, and procedures for reporting fraud.

Some participants with hearing loss were wary of conflicting political and financial interests, others said they would trust information from HCFA on provider selection criteria and referral sources.

Most participants with hearing loss felt they had enough information to choose supplemental insurance. Some were not sure they get good value for the money they spend on supplemental plans. The latter beneficiaries would benefit from tools designed to help them comparison shop more effectively.

Participants with hearing loss did not need information about preventive practices related to hearing loss. However, these participants thought many seniors do need information about preventing or dealing with hearing loss. They noted that primary care providers often don't have sufficient knowledge and experience to help their patients identify the options available to those who face a new hearing loss.

Medicare isn't currently the first source of information about hearing loss for low hearing beneficiaries because the program doesn't cover many hearing-related needs. Participants indicated they need help locating information about assistive devices and making appropriate selections. They would trust information from HCFA if the agency developed a higher profile in this area.

### **How can information be most effectively made available to beneficiaries who have hearing loss?**

Participants with hearing loss appear to want more information from HCFA, as indicated by the gap between amount of information received and trust.

Medical providers are an important source of Medicare information for hard-of-hearing participants: they ranked providers second for amount of information and first for trust.

Although participants rated hearing health care specialists highly for the amount of information they provide related to hearing loss, this is not an important source of Medicare information.

Hard-of-hearing participants rated family and friends, insurance companies that pay Medicare claims, the media, supplemental insurance companies, and community resources similarly to the general population.

Some participants with hearing loss criticized the manner in which information is presented in the Medicare Handbook. They want the Handbook to contain plain language, more widely-spaced text, and examples of the real situations beneficiaries face.

Many beneficiaries with hearing loss like to watch health-related programs on television, and closed-captioning is critical for them. They would like television programs, videos, and commercials to be captioned.

Participants with hearing loss rely on teletypewriters (TTY) to communicate over the telephone. They reported problems trying to contact HCFA this way. They suggested that HCFA display the Medicare TTY number more prominently, and that customer service representatives be trained in using TTY technology and in interacting with low hearing callers.

Several low hearing participants reported problems with automated telephone menus similar to those reported by general population participants. These problems are exacerbated by hearing loss and the clumsy interface between these menus and text telephones.

For many participants with hearing loss, obtaining information in-person is most desirable. They like seminars and roundtable discussions, and they prefer face-to-face conversations because they can lip read as they try to hear what's being said.

Several participants with hearing loss already use computers to obtain information, and they like the interactive features of the Internet.

### **6.3 BENEFICIARIES WITH VISION LOSS**

#### **What information do beneficiaries with vision loss want and need from HCFA?**

Participants with vision loss want information about the Medicare program that is easy to locate and understand.

Despite the fact that many participants with vision loss already know who to contact with Medicare-related questions, their knowledge gaps about aspects of the Medicare program are similar to those in the general population. Both sets of beneficiaries need information about costs, eligibility, coverage, and changes in the program.

Beneficiaries with vision loss particularly want information about Medicare coverage of health services related to vision loss. They would also value information from HCFA about the availability and suitability of assistive vision devices.

None of the participants with vision loss reported wanting to receive information from HCFA that would help them select a health care provider. In the case of vision care specialists, participants prefer to rely on friends and family for recommendations rather than relying on their primary care providers as they do for most other kinds of specialists.

Some beneficiaries with vision loss find that choosing a supplemental insurer is complicated and difficult. They would benefit from help sifting through their options.

Participants with low vision are able to obtain information about general preventive care from a variety of sources, but they'd like more information about preventive vision care.

**How can information be most effectively made available to beneficiaries with vision loss?**

Beneficiaries with vision loss rely heavily on friends and family to pass along information they themselves may miss because they can't see very well. Low vision participants said they put much trust in this source.

Radio is a significant information source for many low vision participants who can no longer see to read a newspaper or watch television. They don't always trust this source, however.

Participants with low vision would like to receive more information from HCFA. One suggestion was for HCFA to provide information about the existence and availability of assistive devices.

Vision specialists and consumer organizations related to vision loss were important sources of information for a significant number of low vision focus group participants.

Most participants with vision loss either want the Handbook on audio-cassette tape, or would like it presented in large, bold print, with strong contrast. Content-related suggestions were similar to those from the general beneficiary population.



The radio is extremely important to participants with vision loss. They rely on stations that perform services for people with low vision, such as reading newspaper articles. Participants with vision loss want more access to programs about vision ailments. Videotapes and television are less important media for those with low vision.

Some participants with vision loss can still read and use print media. Many were interested in other ways of receiving information, such as on audio-cassette tapes or at seminars and roundtable discussions.

Participants who can read on their own, usually with the help of assistive devices, strongly emphasized the need for large print materials.

Participants with low vision need more information about current technology and programs for people with vision loss. This is especially important because these technologies often facilitate independent living.

Participants with vision loss were unenthusiastic about computers. Difficulties with transportation, coupled with the high cost of obtaining a personal computer (and assistive devices for seeing it) makes this medium unattractive for many low vision beneficiaries.

Participants with vision loss reported frustrations with automated telephone menus that were similar to those reported by general population participants. These frustrations are compounded by vision loss. Participants with low vision often can't distinguish keypad numbers when dialing, and they can't use telephone directories to look up phone numbers because the print is too small.

## **APPENDIX A**

### **Market Research for Medicare Beneficiaries Discussion Guides for Low Education, Hearing Loss, and Low Vision Focus Groups**

**HCFA On-line: Market Research for Medicare Beneficiaries**  
**Focus Group Protocol**  
May 1997

- **I. Introduction [5 minutes]**

- Good afternoon (evening) and welcome to our session. My name is \_\_\_\_\_. I work for Westat, a research firm located just outside of Washington, DC. As you may have been told, the Health Care Financing Administration (HCFA), the Federal agency in charge of Medicare, has hired us to come and speak to folks like yourselves about the information you need about the Medicare program and more generally about the information you need about your health and health care.
- The technique I am using today is called a focus group. We are going to focus our discussions on information about Medicare and information about your health. Before we begin, let me remind you of some ground rules.
- We will be on a first name basis only. *[MAKE SURE ALL NAME CARDS FACE TOWARD YOU AND THAT NONE ARE OBSTRUCTED]*
- There are no right or wrong answers in this room--just your opinions. I need to hear what each of you thinks about the topics we are going to discuss, so please speak up. Feel free to disagree, but please wait your turn to speak. You may refer to each other, but please use only the first names on the name cards. Only one person should talk at time.
- Behind me is a one-way mirror. There is a colleague from Westat [and some representatives from Medicare] who will be watching. They want to learn as much as possible from your opinions. We are also tape recording the session because we don't want to miss any of your comments.

- This is a research project. There will be a report written about what we have learned from you and from other people we are talking with both in this area and in other parts of the country. Some of your words may be part of our report; however, no names will be used in the report, and Medicare won't be given any names or information about you. What you say will have no effect on your Medicare benefits, so please be frank. What you say will help Medicare be more responsive to the information needs of beneficiaries.
- Our session will last about an hour and a half to two hours.
- Are there any questions before we begin? Just a few logistics. The restroom facilities are located \_\_\_\_\_. There are no scheduled breaks since we have so much to discuss. However, please feel free to excuse yourself if necessary.
- I've passed out an Information Sheet. Let's take a minute or two and fill out the front of that sheet. We'll get to the back in just a few minutes.
- Let's start our discussion by going around the table. Introduce yourself and tell us what got you interested in this discussion about health and health care. I'll start.

- **II. Information about the Medicare program**
- **A. Who is “Medicare”? [10 minutes maximum]**
- You’re all here because you are enrolled in Medicare, which is a health insurance plan for people over 65 and for some people under 65 who are disabled. Almost everybody in the United States over 65 is on Medicare. My first question for you is, Who do you think of when I say “Medicare”?
- *Probe if needed:* Is it a government agency or an insurance company or what?
- *Encourage some discussion, but limit this section.*
- *If no one mentions HCFA, probe:* Do you know who runs the Medicare program?
- *If no one mentions HCFA still:* Have you heard of the Health Care Financing Administration?
- *If no one knows who HCFA is, say:* The Health Care Financing Administration is the Federal government agency that manages the Medicare program. They are part of the Department of Health and Human Services. Do you remember seeing the name on any letters or pamphlets from Medicare or on the Medicare Handbook?

- **B. Recent experiences getting information about Medicare [20 minutes]**

- I'd like you to think about a time recently that you tried to get information about the Medicare program -- any kind of information at all. What information have you tried to get recently?
- *OPTIONAL: On a flip chart or white board with two columns, write the information items desired as they are reported. As an information item is reported, ask if others have tried to get the same information.*
- *After all information items recorded: From whom did you try to get this information?*
- *Record sources on flip chart, match up with information items. As a source is mentioned, ask if others have tried to get information from that source.*
- *After getting sources, follow up on each source/item reported (or as many as time allows).*
- What form was the information in? (i.e., booklet, letter, Q&A, audio, video, on-line) Did you understand the information? Was it accurate and complete? Was it what you needed?

- |   |
|---|
| <ul style="list-style-type: none"><li>• <i>If anyone mentions "Medicare" as a source of information, probe:</i></li><li>• Who do you mean when you say "Medicare" -- what was the name of the organization you called? [Did you call the government agency that manages the program, an insurance company that pays the claims, or whom?]</li></ul> |
|---|

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- **C. Card sort -- where received information about Medicare [20 minutes]**
- Next, I'd like you to think about all of the sources from which you have received information about the Medicare program. On the table in front of you are several sets of cards. I'd like you to take stack number 1 now. Each of the cards in Stack 1 has one possible source of Medicare information. Let me read the sources:
  - A. your family or friends;
  - B. the insurance companies that pay claims for Medicare;
  - C. your doctors, nurses, or clinics;
  - D. radio, television, and newspapers;
  - E. the Health Care Financing Administration (the Federal government agency that manages Medicare);
  - F. your supplemental insurance company; [Medicaid/your HMO]
  - G. people in your community, such as at senior centers, churches, libraries, etc.;
  - H. organizations such as AARP and magazines for senior citizens. [not for disabled group]
- What I'd like you to do is to sort the cards in order by how much information about Medicare you have received from each source. That is, you would put the card for the source from which you have received the most information on top, the one for the next most information under that, and so on, with the source from which you have received the least information on the bottom.
- Are there any questions?
- *When everyone has finished, ask them to record in Column II of the Information Sheet the letter of each card next to the number of its order in the stack -- the top card is number 1, etc.*

- What did you have as the top card? *Encourage discussion of choices for top one or two information sources.*
- *Throughout this exercise, as participants mention Medicare carriers, HCFA, or supplemental insurers, probe to determine whether they are clear on which one they are talking about*
- *After discussion of sources providing the most information:* Are these sources you've selected at the top of your list particularly convenient or inconvenient ways for you to get information?
- And which card did you have on the bottom? *Encourage discussion of choices for bottom one or two information sources.*
- *After discussion of sources providing the least information:* Are these sources you've selected at the bottom of your list particularly convenient or inconvenient ways for you to get information?
- Are there any information sources that you use that we didn't list on one of the cards? Are there any sources you would *like* to use or to use more?

<ul style="list-style-type: none"> <li>• <i>If more than 45 minutes into session, skip the next card sort.</i></li> </ul>
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- Next, I'd like you to sort the same cards again -- this time, by how much you trust the source to give you accurate, complete, and understandable information about Medicare. The top card would be the source you trust the most for information about Medicare, the bottom the source you trust the least.
- *Ask participants to record this card order in Column III on the Information Sheet*
- Now which card was on top? *Encourage discussion of most accurate and understandable sources. Probe as needed:* Why do you trust {SOURCE] to for information about Medicare?
- And which card was on the bottom? *Encourage discussion of least accurate and understandable sources. Probe as needed:* Why don't you trust {SOURCE] to be accurate and understandable?



- **D. Medicare Handbook [5 minutes]**

- *Hold up copy of Medicare Handbook.*
- Do you recognize this? How many do? \_\_\_\_\_
- Do you have one at home? How many do? \_\_\_\_\_
- Do you ever use it? How many do? \_\_\_\_\_
- What kind of information do you look up in it?

<ul style="list-style-type: none"><li>• <i>If more than one hour has passed, skip the following:</i></li></ul>
--

- Is it clear? Does it have information you need? What's missing or not clear? *Encourage discussion of specific uses, if any mentioned.*
-

- **E. Information about Medicare Still Needed [10 minutes]**
- We've talked a lot about the information you *get* about the Medicare program. What about information you *don't* get? Is there information you need but don't get about the Medicare program? *Probe for details of information needs, why information is needed.*
- What about information you get but don't understand? Is there anything about the Medicare program that you don't understand and would like clearer information about? *Probe for details of needs, why information needed.*
- Where or how would you like to get this information? *Follow up with each need mentioned.*

### **III. Information about Supplemental Insurance and Medicare HMOs**

- **A. Information about Supplemental Insurance [10 minutes]**

- People enrolled in Medicare often have other health insurance as well. Some people have what are called supplemental or “Medigap” policies that pay the deductibles, copayments, and for some services Medicare doesn’t cover. Other people have supplemental insurance that covers just long term care, things like stays in a nursing home. Still other people have supplementary coverage through the Medicaid program.
- How many of you have supplementary health insurance that pays for some of the things Medicare doesn’t cover?
- How many of you had a *choice* of different plans for your supplementary coverage?
- Do you feel as though you had enough information about supplementary insurance to make the choice? What other information would you like to have to make this kind of a choice? How would you like to get this information? (In what form and from whom?)
-

- **B. Information about Medicare HMOs [10 minutes]**
- In most parts of the country, people enrolled in Medicare have the option to join a Medicare health maintenance organization, or HMO. Have you heard about these kinds of health plans? (*If response not overwhelming, ask for show of hands.*)
- Is anyone a member of a Medicare HMO? Have you considered joining a Medicare HMO?
- What kinds of information about Medicare HMOs have you received? *If necessary, probe:* Have you received information from the HMOs themselves? Have you received any other kind of information about how Medicare HMOs work? Have you received any information comparing different plans? *If "Yes":* Where did this information come from? How did you get it? Was it helpful?
- Do you feel as though you have enough information about Medicare HMOs? What (other) information would you like to have?
- 
-

- **IV. General Health Information Needs**

- I'd like to change the subject a little at this point. We've been talking about the information you need about the Medicare program and other health insurance and how you get that information. The agency that runs Medicare would like your advice about other health-related information you need and how they might help you get that information. There are many different areas that might be included here -- I'd like to take a few of them one at a time.

- **A. Information about Choosing a Doctor [10 minutes]**

- First, how about choosing a doctor?
- Do you feel like you get the information you need to help you choose a primary care or "regular" doctor?
- *If "Yes":* What information do you get? From whom? How is it presented? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?
- Do you feel like you get the information you need to help you choose a specialist?
- *If "Yes":* What information do you get? From whom? How is it presented? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?

- **B. Information about Staying Healthy [10 minutes]**
- Next, what about information about ways to stay healthy, such as what foods you should eat and what kind of exercise you should get.
- Do you feel like you get the information you need to help stay healthy?
- *If “Yes”:* What information do you get? From whom? How is it presented? Do you trust the information?
- *If “No”:* What information would you like to have? How would you like to get the information?
- *P If preventive services not mentioned:* Do you feel like you get the information you need about preventive medical care, like check-ups, mammography, and flu shots?
- *If “Yes”:* What information do you get? From whom? How is it presented? Do you trust the information?
- *If “No”:* What information would you like to have? How would you like to get the information?

- **D. Other Information Needs [5 minutes]**
- We've talked about getting information about the Medicare program, about choosing a doctor, and about information on staying healthy. These are only some areas dealing with your health and health care in which you might need information. We don't have time to talk in detail about other areas, but I'd like to give you a chance to mention any that you think are important. Remember, we're asking for your advice to the Medicare program about the information you need about health and health care.
- In what other areas do you feel that you need information? *Continue to elicit suggestions, probing for clarity, but do not get into extended discussion about any particular area.*
-

- **E. Sources of Information [15 minutes]**
- We've talked about many different sources of information about your health. I'd like to ask you briefly about a series of sources, and get an idea of what you think is good about the information you get from that source, and what is bad about it. For example, you might like the way information is presented, you might trust one source over another, you might find the some information more suited to your own needs, you might find some information too hard to understand.
- *For each source that has not been thoroughly discussed previously, probe:* What's good about the information you get from [SOURCE]? What's not so good about it?
- *Sources:*
  - your family and friends
  - your doctors or nurses
  - your health insurance plan
  - newspapers, radio, and television
  - AARP or other senior citizens' groups
  - your local library
  - senior centers or other community sources
  - the Medicare program
  - the Surgeon General
  - *other sources mentioned in the discussion*
-



- **F. Information Media [15 minutes]**
- **A. Mass Media**
- Finally, I'd like to talk a bit about the different media through which you get information about your health and health care. By "media," I mean written material, TV or video, telephone conversations, face-to-face conversations, and so on. Again, I'd like you to say a bit about what's good and what's not so good about each medium, or way of getting information.
- *For each medium, probe: What's good about getting health information this way? What's not so good about it? Try to focus discussion on medium, rather than source or content.*
- *Media:*
  - radio and television
  - videos [Has anyone obtained health information from videos, either at home or at a library or community center? What kind of information was it?]
  - newspapers and magazines
  - notices you get in the mail
-

- **B. 800 numbers/automated phone menus**
- What about 800 numbers? How many of you have tried to get information about Medicare or some other health topic by calling an 800 number?
- And how many of you have reached a recorded message asking if you have a touch tone phone when you called an 800 number?
- What do you do when you reach that kind of message, where you might have to enter some numbers to get to where you want to go?
- *If people express anger or frustration about automated phone menus, probe for the reason for the anger/frustration.*
- Suppose you didn't have to do anything other than wait for someone to come on the line. How is that, compared with having to enter numbers?
- How long would you be willing to wait on such a call before you got impatient -- 10 seconds, 30 seconds, a minute, three minutes, five minutes?
- When you have to enter a number from a list the machine reads to you, does the length of the list make a difference to you? How many options do you think is too many (two, three, four, five . . .)?
- How about when you enter one number, and then get to another menu that asks you to enter another number? Is that a problem? How many selections are you willing to make to get what you want (one, two, three, four, five . . .)?

- **C. Computers/Internet**

- One more way to get health information is by using a computer.
- How many of you use computers?
- Do any of you use the Internet? Do you get health information from the Internet?
- HCFA is thinking about helping you get access to computers in public places such as libraries, senior centers, and Medicare offices.
- What would you think about getting (INSERT INFORMATION TYPE) through these computers? Do you think there are any drawbacks to getting this kind of information by computer?
  - (information about how Medicare works)
  - information about supplemental insurance plans
  - (information about managed care plans)
  - general instructions on how to file Medicare claims
  - general information about what's covered and what Medicare pays
  - information about your own personal claims

What would you want to be able to find out about your claims? (Would you want to get basic information about who has filed claims for your care, when the claim was filed, and whether it was paid? Would you want descriptions of services received? Would you want information about the codes and identification numbers on the claim forms?)

Do you think a computer is a good way to get this kind of information? What makes you say that? Do you think there are drawbacks to getting this kind of information by computer? (Do you think people would feel comfortable using a computer to get access to their personal Medicare records?)

- **D. Summary on Sources**
- Now that we've talked about all these different ways of getting information about Medicare and other health-related topics, where would you most like to be able to get health information?

- **IV.        Wrap-up [2 minutes]**
- Thank you very much for your time. This has been very helpful.
- *Describe procedures for getting paid, how to leave, any other logistical details.*
- We have put out some information that you might find helpful. *Say where it is.* Feel free to take one of any of the materials you want. Please don't take more than one, though, because we only brought a limited supply.
- Again, thanks for your help.
- *Table has Medicare Handbook, other HCFA pubs; 15 copies each. Count and record how many are taken of each pub.*

## • Focus Group Information Sheet

- 
- **1. Are you male or female?**
- ☐ Male
- ☐ Female
- **2. How old are you?**
- ☐ under 65
- ☐ 65-69
- ☐ 70-74
- ☐ 75-79
- ☐ 80-84
- ☐ 85 or older
- **3. Do you take care of your own paperwork for Medicare, or does someone else, like your husband or wife or a child, do it for you?**
- ☐ Do it myself
- ☐ Someone else does it
- **4. Are you of Hispanic origin (e.g., Cuban, Mexican, Puerto Rican, Latino)?**
- ☐ Yes
- ☐ No
- 
- **5. What is your race?**
- ☐ White
- ☐ Black or African-American
- ☐ Asian or Pacific Islander
- ☐ American Indian or Alaska Native
- ☐ Other
- **6. How far did you get in school?**
- ☐ 6th grade or less
- ☐ 7th grade through 12th grade
- ☐ High school graduate
- ☐ Some college
- ☐ College graduate
- ☐ Graduate degree
- **7. Have you ever been in a focus group before?**
- ☐ Yes
- ☐ No

**First Card Sort**  
**Where you get information**

- (Most information)

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

6. \_\_\_\_\_

7. \_\_\_\_\_

8. \_\_\_\_\_

- (Least information)

**Second Card Sort**  
**(How much trust)**

- (Most trust)

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

6. \_\_\_\_\_

7. \_\_\_\_\_

8. \_\_\_\_\_

- (Least trust)

**HCFA On-line: Market Research for Hard-of-Hearing  
Medicare Beneficiaries  
Focus Group Protocol  
November 1997**

- **I. Introduction [5 minutes]**

- Before we start the session I want to make sure the assistive listening system is working. Can everyone hear me (Make any adjustments before starting group . . .)
- Good (morning) (afternoon) and welcome to our session. My name is Brenda Battat. I work for SHHH, the major national organization for hard of hearing people, based here in Bethesda, MD. As you may have been told, the Health Care Financing Administration (HCFA), the Federal agency in charge of Medicare, has hired us to come and speak to folks like yourselves about the information you need about the Medicare program and more generally about the information you need about your health and health care.
- The technique I am using today is called a focus group. We are going to focus our discussions on information about Medicare and information about your health. Before we begin, let me remind you of some ground rules.
- We will be on a first name basis only. *[MAKE SURE ALL NAME CARDS FACE TOWARD YOU AND THAT NONE ARE OBSTRUCTED]*
- There are no right or wrong answers in this room--just your opinions. I need to hear what each of you thinks about the topics we are going to discuss, so please speak up. Feel free to disagree, but please wait your turn to speak. You may refer to each other, but please use only the first names on the name cards. Only one person should talk at a time. Please speak slowly and clearly. Raise your hand if you need something repeated.
- Behind me is a one-way mirror. There are representatives from Medicare and Westat who will be watching. They want to learn as much as possible from your opinions. We are also tape recording the session because we don't want to miss any of your comments.



- This is a research project. There will be a report written about what we have learned from you and from other groups both in this area and in other parts of the country. Some of your words may be part of the report; however, no names will be used in the report, and Medicare won't be given any names or information about you. What you say will have no effect on your Medicare benefits, so please be frank. What you say will help Medicare be more responsive to the information needs of beneficiaries.
- Our session will last about an hour and a half to two hours.
- Are there any questions before we begin? Just a few logistics. The restroom facilities are located \_\_\_\_\_. There are no scheduled breaks since we have so much to discuss. However, please feel free to excuse yourself if necessary.
- I've passed out an Information Sheet. Let's take a minute or two and fill out the front of that sheet. We'll get to the back in just a few minutes.
- Let's start our discussion by going around the table. Introduce yourself and tell us very briefly about your hearing loss. I'll start.

- **II. Information About the Medicare Program**
- **A. Who is “Medicare”? [10 minutes maximum]**
- You’re all here because you are enrolled in Medicare, which is a health insurance plan for people over 65 and for some people under 65 who are disabled. Almost everybody in the United States over 65 is on Medicare. My first question for you is, Who do you think of when I say “Medicare”?
- *Probe if needed:* Is it a government agency or an insurance company or what?
- *Encourage some discussion, but limit this section.*
- *If no one mentions HCFA, probe:* Do you know who runs the Medicare program?
- *If no one mentions HCFA still:* Have you heard of the Health Care Financing Administration?
- *If no one knows who HCFA is, say:* The Health Care Financing Administration is the Federal government agency that manages the Medicare program. They are part of the Department of Health and Human Services. Do you remember seeing the name on any letters or pamphlets from Medicare or on the Medicare Handbook?

- **B. Recent Experiences Getting Information About Medicare [20 Minutes]**

- I'd like you to think about a time recently that you tried to get information about the Medicare program -- any kind of information at all. What information have you tried to get recently?
- From whom did you try to get this information? How did you ask for the information? (e.g., by phone, on-line) Was a TTY number available to you?
- What form was the information in? (i.e., booklet, letter, Q&A, audio, video, on-line) Did you understand the information? Was it accurate and complete? Was it what you needed? Was the information accessible to you? For instance, could you hear the person on the phone? Was the video captioned?

- |   |
|---|
| <ul style="list-style-type: none"><li>• <i>If anyone mentions "Medicare" as a source of information, probe:</i></li><li>• Who do you mean when you say "Medicare" -- what was the name of the organization you called? [Did you call the government agency that manages the program, an insurance company that pays the claims, or whom?]</li></ul> |
|---|

-

- **C. Card Sort -- Where Received Information About Medicare [20 minutes]**
- Next, I'd like you to think about all of the sources from which you have received information about the Medicare program. On the table in front of you is a set of cards. Each of the cards has one possible source of Medicare information. Let me read the sources:
  - A. your family or friends;
  - B. the insurance companies that pay claims for Medicare;
  - C. your doctors or nurses;
  - D. radio, television, and newspapers;
  - E. the Health Care Financing Administration (the Federal government agency that manages Medicare);
  - F. your supplemental insurance company; [Medicaid/your HMO]
  - G. people in your community, such as at senior centers, churches, libraries, etc.;
  - H. organizations such as AARP and magazines for senior citizens;
  - I. hearing health care specialists (e.g., audiologists, speech pathologists, or hearing aid specialists); and
  - J. consumer organizations related to hearing loss.
- (1.) What I'd like you to do is to sort the cards in order by how much information about Medicare you have received from each source. That is, you would put the card for the source from which you have received the most information on top, the one for the next most information under that, and so on, with the source from which you have received the least information on the bottom.
- Are there any questions?
- *When everyone has finished, ask them to record in Column I of the Information Sheet the letter of each card next to the number of its order in the stack -- the top card is number 1, etc.*

- What did you have as the top card? *Encourage discussion of choices for top one or two information sources.*
- *Throughout this exercise, as participants mention Medicare carriers, HCFA, or supplemental insurers, probe to determine whether they are clear on which one they are talking about*
- *After discussion of sources providing the most information:* Are these sources you've selected at the top of your list particularly convenient or inconvenient ways for you to get information?
- And which card did you have on the bottom? *Encourage discussion of choices for bottom one or two information sources.*
- *After discussion of sources providing the least information:* Are these sources you've selected at the bottom of your list particularly convenient or inconvenient ways for you to get information?
- Are there any information sources that you use that we didn't list on one of the cards? Are there any sources you would *like* to use or to use more?
- (2.) Next, I'd like you to sort the same cards again -- this time, by how much you trust the source to give you accurate, complete, and understandable information about Medicare. The top card would be the source you trust the most for information about Medicare, the bottom the source you trust the least.
- *Ask participants to record this card order in Column II on the Information Sheet*
- Now which card was on top? *Encourage discussion of most accurate and understandable sources. Probe as needed:* Why do you trust {SOURCE} to for information about Medicare?
- And which card was on the bottom? *Encourage discussion of least accurate and understandable sources. Probe as needed:* Why don't you trust {SOURCE} to be accurate and understandable?

- **D. Information Media [15 minutes]**
- Now, I'd like to talk a bit about the different media through which you get information about your health and health care. By "media," I mean written material, TV or video, telephone conversations, face-to-face conversations, and so on. Again, I'd like you to say a bit about what's good and what's not so good about each medium, or way of getting information.
- *For each medium, probe: What's good about getting health information this way? What's not so good about it? Try to focus discussion on medium, rather than source or content.*
- *Media:*
  - Radio and television. Was the TV program/advertisement captioned?
  - Videos. [Has anyone obtained health information from videos, either at home or at a library or community center? What kind of information was it?]. Was the video captioned?
  - Newspapers and magazines
  - Notices you get in the mail
  - Telephone conversations. Could you understand the other party? Did they speak slowly and clearly? Have you called for information through the relay? Was the other party familiar/comfortable using the relay with you? Have you called for information via TTY? Was your call answered? Was the number easy to locate? Was it listed along with the voice phone number?
  - Face-to-face conversations. Could you understand the person well enough? Was an assistive device available for your use? Was the meeting in a quiet location?
-

- **800 numbers/automated phone menus**
- What about 800 numbers? How many of you have tried to get information about Medicare or some other health topic by calling an 800 number?
- And how many of you have reached a recorded message asking if you have a touch tone phone when you called an 800 number?
- What do you do when you reach that kind of message, where you might have to enter some numbers to get to where you want to go?
- *If people express anger or frustration about automated phone menus, probe for the reason for the anger/frustration. Skip the bracketed questions if they seem inappropriate or irrelevant.*
- [[[Suppose you didn't have to do anything other than wait for someone to come on the line. How is that, compared with having to enter numbers?
- How long would you be willing to wait on such a call before you got impatient -- 10 seconds, 30 seconds, a minute, three minutes, five minutes?
- When you have to enter a number from a list the machine reads to you, does the length of the list make a difference to you? How many options do you think is too many (two, three, four, five . . .)?
- How about when you enter one number, and then get to another menu that asks you to enter another number? Is that a problem? How many selections are you willing to make to get what you want (one, two, three, four, five . . .)?]]]
- How many of you have trouble hearing the recorded message? Why?
- What do you do when you reach a recorded message and cannot hear the instructions?
- Would you prefer another way of getting information? How would you prefer to get information?
- How many have used the relay to call the 800 number?

- **Computers/Internet**
- One more way to get health information is by using a computer.
- How many of you use computers?
- Do any of you use the Internet? Do you get health information from the Internet?
- HCFA is thinking about helping you get access to computers in public places such as libraries, senior centers, and Medicare offices.
- What would you think about getting (INSERT INFORMATION TYPE) through these computers? Do you think there are any drawbacks to getting this kind of information by computer?
  - (information about how Medicare works)
  - information about supplemental insurance plans
  - (information about managed care plans)
  - general instructions on how to file Medicare claims
  - general information about what's covered and what Medicare pays
  - information about your own personal claims

What would you want to be able to find out about your claims? (Would you want to get basic information about who has filed claims for your care, when the claim was filed, and whether it was paid? Would you want descriptions of services received? Would you want information about the codes and identification numbers on the claim forms?)

Do you think a computer is a good way to get this kind of information? What makes you say that? Do you think there are drawbacks to getting this kind of information by computer? (Do you think people would feel comfortable using a computer to get access to their personal Medicare records?)

-



- **E. Medicare Handbook [5 minutes]**

- *Hold up copy of Medicare Handbook.*
- Do you recognize this? How many do? \_\_\_\_\_
- Do you have one at home? How many do? \_\_\_\_\_
- Do you ever use it? How many do? \_\_\_\_\_
- What kind of information do you look up in it?

<ul style="list-style-type: none"><li>• <i>If more than one hour has passed, skip the following:</i></li></ul>
--

- Is it clear? Does it have information you need? What's missing or not clear? *Encourage discussion of specific uses, if any mentioned.*
-

- **F. Information About Medicare Still Needed [10 minutes]**
- We've talked a lot about the information you *get* about the Medicare program. What about information you *don't* get? Is there information you need but don't get about the Medicare program? *Probe for details of information needs, why information is needed.*
- What about information you get but don't understand? Is there anything about the Medicare program that you don't understand and would like clearer information about? *Probe for details of needs, why information needed.*
- Where or how would you like to get this information? *Follow up with each need mentioned.*

- **III. Information About Supplemental Insurance [10 minutes]**
- People enrolled in Medicare often have other health insurance as well. Some people have what are called supplemental or “Medigap” policies that pay the deductibles, copayments, and for some services Medicare doesn’t cover. Other people have supplemental insurance that covers just long term care, things like stays in a nursing home. Still other people have supplementary coverage through the Medicaid program.
- How many of you have supplementary health insurance that pays for some of the things Medicare doesn’t cover?
- How many of you had a *choice* of different plans for your supplementary coverage?
- Do you feel as though you had enough information about supplementary insurance to make the choice? What other information would you like to have to make this kind of a choice? How would you like to get this information? (In what form and from whom?)

- **IV. General Health Information Needs**
- I'd like to change the subject a little at this point. We've been talking about the information you need about the Medicare program and other health insurance and how you get that information. The agency that runs Medicare would like your advice about other health-related information you need and how they might help you get that information. There are many different areas that might be included here -- I'd like to take a few of them one at a time.
- **A. Information About Choosing a Doctor [10 minutes]**
- First, how about choosing a doctor?
- Do you feel like you get the information you need to help you choose a primary care or "regular" doctor?
- *If "Yes":* What information do you get? From whom? Is the information presented in an accessible format for you? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?
- Do you feel like you get the information you need to help you choose a specialist?
- *If "Yes":* What information do you get? From whom? Is the information presented in an accessible format for you? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?
- Do you feel like you get the information you need to help you choose a professional to treat your hearing loss?
- *If "Yes":* What information do you get? From whom? Is the information presented in an accessible format for you? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?

- **B. Information About Staying Healthy [10 minutes]**
- Next, what about information about ways to stay healthy, such as what foods you should eat and what kind of exercise you should get.
- Do you feel like you get the information you need to help stay healthy?
- *If “Yes”:* What information do you get? From whom? How is it presented? Do you trust the information?
- *If “No”:* What information would you like to have? How would you like to get the information?
- Do you feel like you get the information you need about hearing testing, hearing aids, wax build-up in your ears, and protecting your hearing?
- *P If preventive services not mentioned:* Do you feel like you get the information you need about preventive medical care, like check-ups, mammography, and flu shots?
- *If “Yes”:* What information do you get? From whom? How is it presented? Do you trust the information?
- *If “No”:* What information would you like to have? How would you like to get the information?

- **D. Other Information Needs [5 minutes]**
- We've talked about getting information about the Medicare program, about choosing a doctor, and about information on staying healthy. These are only some areas dealing with your health and health care in which you might need information. We don't have time to talk in detail about other areas, but I'd like to give you a chance to mention any that you think are important. Remember, we're asking for your advice to the Medicare program about the information you need about health and health care.
- In what other areas do you feel that you need information? *Continue to elicit suggestions, probing for clarity, but do not get into extended discussion about any particular area.*
-

- **E. Sources of Information [15 minutes]**
- We've talked about many different sources of information about your health. I'd like to ask you briefly about a series of sources, and get an idea of what you think is good about the information you get from that source, and what is bad about it. For example, you might like the way information is presented, you might trust one source over another, you might find the some information more suited to your own needs, you might find some information too hard to understand.
- *For each source that has not been thoroughly discussed previously, probe:* What's good about the information you get from [SOURCE]? What's not so good about it?
- *Sources:*
  - your family and friends
  - your doctors or nurses
  - your health insurance plan
  - newspapers, radio, and television
  - AARP or other senior citizens' or hearing loss-related groups
  - your local library
  - senior centers or other community sources
  - the Medicare program
  - the Surgeon General
  - audiologists, hearing aid specialists
  - *other sources mentioned in the discussion*
- 
- **Summary on Sources**
- Now that we've talked about all these different ways of getting information about Medicare and other health-related topics, where would you most like to be able to get health information?

- **IV.       Wrap-up [2 minutes]**
- Thank you very much for your time. This has been very helpful.
- *Describe procedures for getting paid, how to leave, any other logistical details.*
- We have put out some information that you might find helpful. *Say where it is.* Feel free to take one of any of the materials you want. Please don't take more than one, though, because we only brought a limited supply.
- Again, thanks for your help.
- *Table has Medicare Handbook, other HCFA pubs; 15 copies each. Count and record how many are taken of each pub.*



## • Focus Group Information Sheet

- **1. Are you male or female?**
  - ☐ Male
  - ☐ Female
- **2. How old are you?**
  - ☐ under 65
  - ☐ 65-69
  - ☐ 70-74
  - ☐ 75-79
  - ☐ 80-84
  - ☐ 85 or older
- **3. Do you take care of your own paperwork for Medicare, or does someone else, like your husband or wife or a child, do it for you?**
  - ☐ Do it myself
  - ☐ Someone else does it
- **4. Are you of Hispanic origin (e.g., Cuban, Mexican, Puerto Rican, Latino)?**
  - ☐ Yes
  - ☐ No
- **5. What is your race?**
  - ☐ White
  - ☐ Black or African-American
  - ☐ Asian or Pacific Islander
  - ☐ American Indian or Alaska Native
  - ☐ Other
- **6. How far did you get in school?**
  - ☐ 6th grade or less
  - ☐ 7th grade through 12th grade
  - ☐ High school graduate
  - ☐ Some college
  - ☐ College graduate
  - ☐ Graduate degree
- **7. Have you ever been in a focus group before?**
  - ☐ Yes
  - ☐ No
- **8. What level is your hearing loss?**
  - ☐ Mild
  - ☐ Moderate
  - ☐ Severe
  - ☐ Profound
- **9. Do you use hearing aids?**
  - ☐ Yes
    - ☐ In one ear
    - ☐ In both ears
    - ☐ Cochlear implant
  - ☐ No

**First Card Sort  
(Where you get information)**

- (Most information)

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

6. \_\_\_\_\_

7. \_\_\_\_\_

8. \_\_\_\_\_

9. \_\_\_\_\_

10. \_\_\_\_\_

- (Least information)

**Second Card Sort  
(How much trust)**

- (Most trust)

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

6. \_\_\_\_\_

7. \_\_\_\_\_

8. \_\_\_\_\_

9. \_\_\_\_\_

10. \_\_\_\_\_

- (Least trust)

**HCFA On-line: Market Research for Low Vision Medicare Beneficiaries**  
**Focus Group Protocol**  
January 1998

- **I. Introduction [5 minutes]**

- Good (morning) (afternoon) and welcome to our session. My name is Elaine Yatzkan. I work for the Jewish Guild for the Blind, the oldest health care vision organization in the country, located in New York City. As you may have been told, the Health Care Financing Administration (HCFA), the Federal agency in charge of Medicare, has hired us to come and speak to folks like yourselves about the information you need about the Medicare program and more generally about the information you need about your health and health care. Now you're all here because you've experienced some level of vision loss. Medicare has talked to all sorts of people about what information they need, but only you can tell us about those specific needs related to your vision loss.
- The technique I am using today is called a focus group. We are going to focus our discussions on information about Medicare and information about your health. Before we begin, let me remind you of some ground rules.
- We will be on a first name basis only. We have name cards here, but since some of you may have trouble seeing them, please identify yourselves when you speak so that we'll know who's speaking. *[MAKE SURE ALL NAME CARDS FACE TOWARD YOU AND THAT NONE ARE OBSTRUCTED]*
- There are no right or wrong answers in this room--just your opinions. I need to hear what each of you thinks about the topics we are going to discuss, so please speak up. Feel free to disagree, but please wait your turn to speak. You may refer to each other, but please use only the first names on the name cards. Only one person should talk at time.
- Behind me is a one-way mirror. There is a colleague from Westat, a research firm [and some representatives from Medicare] who will be watching. They want to learn as much as possible from your opinions. We are also tape recording the session because we don't want to miss any of your comments.

- This is a research project. There will be a report written about what we have learned from you and from other people we are talking with both in this area and in other parts of the country. Some of your words may be part of our report; however, no names will be used in the report, and Medicare won't be given any names or information about you. What you say will have no effect on your Medicare benefits, so please be frank. What you say will help Medicare be more responsive to the information needs of beneficiaries.
- Our session will last about an hour and a half to two hours.
- Are there any questions before we begin? Just a few logistics. The restroom facilities are located [give specific directions]. There are no scheduled breaks since we have so much to discuss. However, please feel free to excuse yourself if necessary. [Name of helper], whom you met earlier, will be happy to provide any help you might need.
- Let's start our discussion by going around the table. Introduce yourself and tell us very briefly about your vision loss. I'll start.

- **II. Information about the Medicare program**
- **A. Who is “Medicare”? [10 minutes maximum]**
- You’re all here because you are enrolled in Medicare, which is a health insurance plan for people over 65 and for some people under 65 who are disabled. Almost everybody in the United States over 65 is on Medicare. My first question for you is, Who do you think of when I say “Medicare”?
- *Probe if needed:* Is it a government agency or an insurance company or what?
- *Encourage some discussion, but limit this section.*
- *If no one mentions HCFA, probe:* Do you know who runs the Medicare program?
- *If no one mentions HCFA still:* Have you heard of the Health Care Financing Administration?
- *If no one knows who HCFA is, say:* The Health Care Financing Administration is the Federal government agency that manages the Medicare program. They are part of the Department of Health and Human Services.

- **B. Recent experiences getting information about Medicare [20 minutes]**
  - I'd like you to think about a time recently that you tried to get information about the Medicare program -- any kind of information at all. What information have you tried to get recently?
  - From whom did you try to get this information?
  - What form was the information in? (i.e., booklet, letter, Q&A, audio, video, on-line) Did you understand the information? Was it accurate and complete? Was it what you needed? Was the information accessible to you?
- |  |
|--|
| <ul style="list-style-type: none"> <li>• <i>If anyone mentions "Medicare" as a source of information, probe:</i></li> <li>• Who do you mean when you say "Medicare" -- what was the name of the organization you called? [Did you call the government agency that manages the program, an insurance company that pays the claims, or whom?]</li> </ul> |
|--|

-

- **C. Where information about Medicare comes from [20 minutes]**
- Next, I'd like you to think about all of the sources from which you have received information about the Medicare program. Some of those sources might be:
  - A. your family or friends;
  - B. the insurance companies that pay claims for Medicare;
  - C. your doctors, nurses, or clinics;
  - D. radio, television, and newspapers;
  - E. the Health Care Financing Administration (the Federal government agency that manages Medicare);
  - F. your supplemental insurance company; [Medicaid/your HMO]
  - G. people in your community, such as at senior centers, churches, libraries, etc.;
  - H. organizations such as AARP and magazines for senior citizens. [not for disabled group]
  - I. other organizations related to vision loss (such as the Pennsylvania Council for the Blind, the Macular Degeneration Society, or the Council for Citizens with Low Vision)
- What I'd like you to do is tell me which source or sources you've gotten the most information from. In other words, who gives you the most information about Medicare; who do you turn to the most often when you have questions about the Medicare program? Are there features of these sources that are particularly important to people with vision loss? *Encourage discussion of choices for top one or two information sources, focusing on how vision loss affects choices.*
- *Throughout this exercise, as participants mention Medicare carriers, HCFA, or supplemental insurers, probe to determine whether they are clear on which one they are talking about*
- *After discussion of sources providing the most information:* Are these sources you've selected as providing the most information particularly convenient or inconvenient ways for you to get information? Do you think that's related to your vision loss?
- Which sources provide the least amount of information? *Encourage discussion of choices for bottom one or two information sources.*

- *After discussion of sources providing the least information:* Are these sources you've selected as providing the least information particularly convenient or inconvenient ways for you to get information? Do you think that's related to your vision loss?
- Are there any information sources that you use that haven't talked about? Are there any sources you would *like* to use or to use more?

<ul style="list-style-type: none"> <li>• <i>If more than 45 minutes into session, skip the next card sort.</i></li> </ul>
---

- Next, I'd like you to think about how much you trust each of these sources to give you accurate, complete, and understandable information about Medicare. *Repeat the list of sources as needed.*
- Which source or sources do you trust the most? *Encourage discussion of most accurate and understandable sources. Probe as needed:* Why do you trust [SOURCE] to provide accurate and understandable information about Medicare?
- Which source do you trust the least? *Encourage discussion of least accurate and understandable sources. Probe as needed:* Why don't you trust [SOURCE] to be accurate and understandable?



- **F. Information Media [15 minutes]**
- Finally, I'd like to talk a bit about the different media through which you get information about your health and health care. By "media," I mean written material, TV, radio, or video, telephone conversations, face-to-face conversations, and so on. Again, I'd like you to say a bit about what's good and what's not so good about each medium, or way of getting information.
- *For each medium, probe:* What's good about getting health information this way? What's not so good about it? How is that related to your vision loss? *Try to focus discussion on medium, rather than source or content.*
- *Media:*
  - radio and television
  - videos [Has anyone been able to obtain health information from videos, either at home or at a library or community center? What kind of information was it?]
  - newspapers and magazines
  - notices you get in the mail
  - In-touch network
  - Cassettes (i.e. talking books)
-

- **800 numbers/automated phone menus**
- What about 800 numbers? How many of you have tried to get information about Medicare or some other health topic by calling an 800 number?
- And how many of you have reached a recorded message asking if you have a touch tone phone when you called an 800 number?
- What do you do when you reach that kind of message, where you might have to enter some numbers to get to where you want to go?
- *If people express anger or frustration about automated phone menus, probe for the reason for the anger/frustration:* What makes using an 800 number difficult for you? Do you think that's related to your vision loss?
- Suppose you didn't have to do anything other than wait for someone to come on the line. How is that, compared with having to enter numbers?
- How long would you be willing to wait on such a call before you got impatient -- 10 seconds, 30 seconds, a minute, three minutes, five minutes?
- When you have to enter a number from a list the machine reads to you, does the length of the list make a difference to you? How many options do you think is too many (two, three, four, five . . .)?
- How about when you enter one number, and then get to another menu that asks you to enter another number? Is that a problem? How many selections are you willing to make to get what you want (one, two, three, four, five . . .)?
- Does your vision impairment make using the telephone more difficult? If yes, in what way?

- **Computers/Internet**
- One more way to get health information is by using a computer.
- How many of you use computers? If not, why not? Does your vision impairment limit your use of the computer?
- Do any of you use the Internet? Do you get health information from the Internet?
- HCFA is thinking about helping you get access to computers in public places such as libraries, senior centers, and Medicare offices.
- What would you think about getting (INSERT INFORMATION TYPE) through these computers? Do you think there are any drawbacks to getting this kind of information by computer?
  - (information about how Medicare works)
  - information about supplemental insurance plans
  - (information about managed care plans)
  - general instructions on how to file Medicare claims
  - general information about what's covered and what Medicare pays
  - information about your own personal claims

What would you want to be able to find out about your claims? (Would you want to get basic information about who has filed claims for your care, when the claim was filed, and whether it was paid? Would you want descriptions of services received? Would you want information about the codes and identification numbers on the claim forms?)

Do you think a computer is a good way to get this kind of information? What makes you say that? Do you think there are drawbacks to getting this kind of information by computer? (Do you think people would feel comfortable using a computer to get access to their personal Medicare records?)

- **D. Medicare Handbook [5 minutes]**

- How many are familiar with the Medicare Handbook? \_\_\_\_\_
- Do you have one at home? How many do? \_\_\_\_\_
- Do you ever use it? How many do? \_\_\_\_\_
- Do you need someone else to read it for you?
- What kind of information do you look up in it?
- What kinds of things might make it easier to use?
- What are some other ways HCFA could get this information to you?

<ul style="list-style-type: none"><li>• <i>If more than one hour has passed, skip the following:</i></li></ul>
--

- Is it clear? Does it have information you need? What's missing or not clear? *Encourage discussion of specific uses, if any mentioned.*
-

- **E. Information about Medicare Still Needed [10 minutes]**
- We've talked a lot about the information you *get* about the Medicare program. What about information you *don't* get? Is there information you need but don't get about the Medicare program? *Probe for details of information needs, why information is needed.*
- What about information you get but don't understand? Is there anything about the Medicare program that you don't understand and would like clearer information about? *Probe for details of needs, why information needed.*
- Where or how would you like to get this information? *Follow up with each need mentioned.*

- **III. Information about Supplemental Insurance [10 minutes]**
- People enrolled in Medicare often have other health insurance as well. Some people have what are called supplemental or “Medigap” policies that pay the deductibles, copayments, and for some services Medicare doesn’t cover. Other people have supplemental insurance that covers just long term care, things like stays in a nursing home. Still other people have supplementary coverage through the Medicaid program.
- How many of you have supplementary health insurance that pays for some of the things Medicare doesn’t cover?
- How many of you had a *choice* of different plans for your supplementary coverage?
- Do you feel as though you had enough information about supplementary insurance to make the choice? What other information would you like to have to make this kind of a choice? How would you like to get this information? (In what form and from whom?)

- **IV. General Health Information Needs**

- I'd like to change the subject a little at this point. We've been talking about the information you need about the Medicare program and other health insurance and how you get that information. The agency that runs Medicare would like your advice about other health-related information you need and how they might help you get that information. There are many different areas that might be included here -- I'd like to take a few of them one at a time.

- **A. Information about Choosing a Doctor [10 minutes]**

- First, how about choosing a doctor?
- Do you feel like you get the information you need to help you choose a primary care or "regular" doctor?
- *If "Yes":* What information do you get? From whom? How is it presented? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?
- Do you feel like you get the information you need to help you choose a specialist?
- *If "Yes":* What information do you get? From whom? How is it presented? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?
- Do you feel like you get the information you need to help you choose a professional to treat your vision loss?
- *If "Yes":* What information do you get? From whom? How is it presented? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?

- **B. Information about Staying Healthy [10 minutes]**
- Next, what about information about ways to stay healthy, such as what foods you should eat and what kind of exercise you should get.
- Do you feel like you get the information you need to help stay healthy?
- *If “Yes”:* What information do you get? From whom? How is it presented? Do you trust the information?
- *If “No”:* What information would you like to have? How would you like to get the information?
- Do you feel like you get the information you need about vision testing, glasses or contacts, and protecting your vision?
- *P If preventive services not mentioned:* Do you feel like you get the information you need about preventive medical care, like check-ups, mammography, and flu shots?
- *If “Yes”:* What information do you get? From whom? How is it presented? Do you trust the information?
- *If “No”:* What information would you like to have? How would you like to get the information?



- **D. Other Information Needs [5 minutes]**
- We've talked about getting information about the Medicare program, about choosing a doctor, and about information on staying healthy. These are only some areas dealing with your health and health care in which you might need information. We don't have time to talk in detail about other areas, but I'd like to give you a chance to mention any that you think are important. Remember, we're asking for your advice to the Medicare program about the information you need about health and health care.
- In what other areas do you feel that you need information? *Continue to elicit suggestions, probing for clarity, but do not get into extended discussion about any particular area.*

## **Summary on Sources**

- Now that we've talked about all these different ways of getting information about Medicare and other health-related topics, where would you most like to be able to get health information?

- **IV.        Wrap-up [2 minutes]**
- Thank you very much for your time. This has been very helpful.
- *Describe procedures for getting paid, how to leave, any other logistical details.*
- We have put out some information that you might find helpful. *Say where it is.* Feel free to take one of any of the materials you want. Please don't take more than one, though, because we only brought a limited supply.
- Again, thanks for your help.
- *Table has Medicare Handbook, other HCFA pubs; 15 copies each. Count and record how many are taken of each pub.*

- **Focus Group Information Sheet**

- **1. Are you male or female?**
- ☐ Male
- ☐ Female
- **2. How old are you?**
- ☐ under 65
- ☐ 65-69
- ☐ 70-74
- ☐ 75-79
- ☐ 80-84
- ☐ 85 or older
- **3. Do you take care of your own paperwork for Medicare, or does someone else, like your husband or wife or a child, do it for you?**
- ☐ Do it myself
- ☐ Someone else does it
- **4. Are you of Hispanic origin (e.g., Cuban, Mexican, Puerto Rican, Latino)?**
- ☐ Yes
- ☐ No
- **5. What is your race?**
- ☐ White
- ☐ Black or African-American
- ☐ Asian or Pacific Islander
- ☐ American Indian or Alaska Native
- ☐ Other
- **6. How far did you get in school?**
- ☐ 6th grade or less
- ☐ 7th grade through 12th grade
- ☐ High school graduate

- ☐ Some college
- ☐ College graduate
- ☐ Graduate degree
- **7. Have you ever been in a focus group before?**
- ☐ Yes
- ☐ No
- **8. What level is your vision loss?**
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- **9. Do you use vision aids?**
- ☐ Glasses/contacts
- ☐ Telescope
- ☐ Other (please specify)
  - \_\_\_\_\_
- ☐ None used
-

## **APPENDIX B**

**HCFA On-line: Market Research for Medicare Beneficiaries  
Focus Group Recruitment Screening Questionnaires  
for Participants with Low Educational Attainment,  
Participants with Hearing Loss, and Participants with Vision Loss**

**Medicare Beneficiaries Focus Groups**  
**Participant Screener: Low Educational Attainment**

THIS SCREENER RECRUITS FOCUS GROUP PARTICIPANTS WHO ARE AGE 65 OR OVER, RECEIVE MEDICARE, BUT DO NOT BELONG TO A HEALTH MAINTENANCE ORGANIZATION (HMO). THESE PARTICIPANTS ALL HAVE LESS THAN A HIGH SCHOOL EDUCATION AND ARE DISTRIBUTED ACROSS GENDER & RACE.

In order to find out if you are eligible to participate in this study, we need to get some background information.

1. How old are you?

:\_\_:\_\_:

[IF UNDER 65, GO TO SKIP]

[IF 65 OR OLDER GO TO 2]

SKIP:

[IF UNDER 64, ASK IF THERE IS SOMEONE ELSE IN THE HOUSEHOLD WHO IS 65 OR OVER THAT YOU COULD SPEAK WITH. IF NOT, THANK AND TERMINATE.]

2. Are you presently receiving benefits from Medicare?

YES :\_\_:

NO :\_\_: [THANK AND TERMINATE INTERVIEW.]

3. Are you enrolled in a Health Maintenance Organization (HMO) through Medicare?

YES :\_\_: [THANK AND TERMINATE INTERVIEW.]

NO :\_\_:

4. Do you regularly receive medical care through the Veterans Administration (VA)?

YES :\_\_: [THANK AND TERMINATE INTERVIEW.]

NO :\_\_:



5. Are you covered by Medicaid or (STATE NAME FOR MEDICAID)?

YES :\_\_: [GO TO Q5a]

NO :\_\_: [GO TO Q6]

5a. So you receive both Medicare and Medicaid benefits?

YES :\_\_: [THANK AND TERMINATE]

NO :\_\_: [CONTINUE SCREENER WITH Q6]

6. [IF NOT OBVIOUS, ASK]

Are you male or female?

MALE :\_\_:

FEMALE :\_\_:

7. Do you consider yourself to be...

White, :\_\_:

Black, :\_\_:

Hispanic, or :\_\_:

some other race/ethnicity? :\_\_:

SPECIFY \_\_\_\_\_

8. What is the highest grade in school that you have completed?

Less than high school diploma; :\_\_: [RECRUIT]

High school graduate; :\_\_:

Some college; :\_\_:

College graduate; or :\_\_:

Advanced degree. :\_\_:

**Medicare Beneficiaries Focus Groups**  
**Participant Screener: Hearing Loss**

THIS SCREENER RECRUITS FOCUS GROUP PARTICIPANTS WHO ARE AGE 65 OR OVER, RECEIVE MEDICARE, BUT DO NOT BELONG TO A HEALTH MAINTENANCE ORGANIZATION (HMO). THESE PARTICIPANTS ARE ALL HEARING-IMPAIRED, DEFINED AS HAVING A LOT OF DIFFICULTY HEARING. THEY ARE DISTRIBUTED ACROSS GENDER, RACE, AND EDUCATIONAL LEVEL.

In order to find out if you are eligible to participate in this study, we need to get some background information.

1. How old are you?

:\_\_:\_\_:

[IF UNDER 65, GO TO SKIP]

[IF 65 OR OLDER GO TO 2]

SKIP:

[IF UNDER 64, ASK IF THERE IS SOMEONE ELSE IN THE HOUSEHOLD WHO IS 65 OR OVER THAT YOU COULD SPEAK WITH. IF NOT, THANK AND TERMINATE.]

2. Are you presently receiving benefits from Medicare?

YES :\_\_:

NO :\_\_: [THANK AND TERMINATE INTERVIEW.]

3. Are you enrolled in a Health Maintenance Organization (HMO) through Medicare?

YES :\_\_: [THANK AND TERMINATE INTERVIEW.]

NO :\_\_:

4. Do you regularly receive medical care through the Veterans Administration (VA)?

YES :\_\_: [THANK AND TERMINATE INTERVIEW.]

NO :\_\_:

5. Are you covered by Medicaid or (STATE NAME FOR MEDICAID)?

YES :\_\_: [GO TO Q5a]

NO :\_\_: [GO TO Q6]

5a. So you receive both Medicare and Medicaid benefits?

YES :\_\_: [THANK AND TERMINATE]

NO :\_\_: [CONTINUE SCREENER WITH Q6]

6. How much difficulty do you have hearing (WITH A HEARING AID IF ONE IS USED)?

NO DIFFICULTY :\_\_: [THANK AND TERMINATE INTERVIEW.]

A LITTLE DIFFICULTY :\_\_: [THANK AND TERMINATE INTERVIEW.]

A LOT OF DIFFICULTY :\_\_: [RECRUIT]

7. [IF NOT OBVIOUS, ASK]

Are you male or female?

MALE :\_\_:

FEMALE :\_\_:

8. Do you consider yourself to be...

White, :\_\_:

Black, :\_\_:

Hispanic, or :\_\_:

some other race/ethnicity? :\_\_:

SPECIFY \_\_\_\_\_

9. What is the highest grade in school that you have completed?

Less than high school diploma; :\_\_:

High school graduate; :\_\_:

Some college; :\_\_:

College graduate; or :\_\_:

Advanced degree. :\_\_:

**Medicare Beneficiaries Focus Groups**  
**Participant Screener: Vision Loss**

THIS SCREENER RECRUITS FOCUS GROUP PARTICIPANTS WHO ARE AGE 65 OR OVER, RECEIVE MEDICARE, BUT DO NOT BELONG TO A HEALTH MAINTENANCE ORGANIZATION (HMO). THESE PARTICIPANTS ARE ALL VISION-IMPAIRED, DEFINED AS HAVING A LOT OF DIFFICULTY SEEING. THEY ARE DISTRIBUTED ACROSS GENDER, RACE, AND EDUCATIONAL LEVEL.

In order to find out if you are eligible to participate in this study, we need to get some background information.

1. How old are you?

:\_\_:\_\_:

[IF UNDER 65, GO TO SKIP]

[IF 65 OR OLDER GO TO 2]

SKIP:

[IF UNDER 64, ASK IF THERE IS SOMEONE ELSE IN THE HOUSEHOLD WHO IS 65 OR OVER THAT YOU COULD SPEAK WITH. IF NOT, THANK AND TERMINATE.]

2. Are you presently receiving benefits from Medicare?

YES :\_\_:

NO :\_\_: [THANK AND TERMINATE INTERVIEW.]

3. Are you enrolled in a Health Maintenance Organization (HMO) through Medicare?

YES :\_\_: [THANK AND TERMINATE INTERVIEW.]

NO :\_\_:

4. Do you regularly receive medical care through the Veterans Administration (VA)?

YES :\_\_: [THANK AND TERMINATE INTERVIEW.]

NO :\_\_:

5. Are you covered by Medicaid or (STATE NAME FOR MEDICAID)?

YES :\_\_: [GO TO Q5a]

NO :\_\_: [GO TO Q6]

5a. So you receive both Medicare and Medicaid benefits?

YES :\_\_: [THANK AND TERMINATE]

NO :\_\_: [CONTINUE SCREENER WITH Q6]

6. How much difficulty do you have seeing (WITH GLASSES OR CONTACTS IF THEY ARE USED)?

NO DIFFICULTY :\_\_: [THANK AND TERMINATE INTERVIEW.]

A LITTLE DIFFICULTY :\_\_: [THANK AND TERMINATE INTERVIEW.]

A LOT OF DIFFICULTY :\_\_: [RECRUIT]

7. [IF NOT OBVIOUS, ASK]

Are you male or female?

MALE :\_\_:

FEMALE :\_\_:

8. Do you consider yourself to be...

White, :\_\_:

Black, :\_\_:

Hispanic, or :\_\_:

some other race/ethnicity? :\_\_:

SPECIFY \_\_\_\_\_

9. What is the highest grade in school that you have completed?

Less than high school diploma; :\_\_:

High school graduate; :\_\_:

Some college; :\_\_:

College graduate; or :\_\_:

Advanced degree. :\_\_: